Virtual nutrition education for people affected by Parkinson's disease

by

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B.S., University of Costa Rica, 2013
M.P.H., Kansas State University, 2017

AN ABSTRACT OF A DISSERTATION

submitted in partial fulfillment of the requirements for the degree

DOCTOR OF PHILOSOPHY

Department of Food, Nutrition, Dietetics, and Health
College of Health and Human Sciences

KANSAS STATE UNIVERSITY
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Abstract

Parkinson's disease is a progressive movement condition and, after Alzheimer's disease, the second most common neurodegenerative disease. Parkinson's disease has no proven cure. However, efforts are being made to improve the quality of life of people with Parkinson’s. Quality of life encompasses a variety of domains, including nutritional health. The progression and severity of Parkinson's disease is linked to nutrient intake and nutrition status.

The period and severity of Parkinson's disease are linked to nutrient intake and nutrition status. Malnutrition, digestive problems, and eating problems impair muscle strength, mass, and cramps, reducing equilibrium and speeding up the progression of Parkinson's disease. A lack of nutrition can increase one's dependency on everyday activities, lowering the person's quality of life.

Scientific publications on the basic benefits of nutrition education services in this population are scarce. Self-management services, which seek to enhance quality of life, assist participants in coping with Parkinson's disease diagnosis while also improving communication and mental health. Some of these initiatives can provide nutrition; however, there is insufficient data to report on the effects. It is essential to consider what knowledge people with Parkinson's disease are interested in and their needs before developing a nutrition self-management education program. Focus groups can assist with gathering this knowledge to create an effective program.

This study aimed to increase nutrition knowledge and improve quality of life through virtual nutrition education to people with Parkinson’s disease and their care partners. This experimental design was a mixed-methods approach, using focus groups to determine topics of interest and pre- and post-self-report data to assess program effectiveness and quality of life.

The study's nutrition education portion was divided into six modules and was eight weeks in duration. Weeks one and eight were for data collection. A total of 28 people enrolled in the virtual program, and fifteen participants completed the pre-and post-surveys (54% completion rate).

Participants were at risk of malnutrition. However, according to their intake report, their total consumption of macro-and micronutrients increased. Additionally, even though quality of life did not have a statistically significant change, six out of 12 participants improved their quality of life scores. Additionally, participants expressed how the program led them to be more aware of healthy eating, gut health, hydration, food-medication interaction, and constipation.

In conclusion, this program was tailored specifically to the knowledge needs of the participants and this population. This virtual program was useful, worthwhile, engaging, and helpful for the participants. Additionally, the program was a resource that helped improve quality of life by providing support through nutrition knowledge.

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Approved by:

Major Professor
Mark Haub

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Dedication

I dedicate my dissertation work to my parents, sisters, and friends that one way or another helped me and supported me throughout all these years.

Chapter 1 - Nutritional changes in Parkinson's disease

Abstract

Parkinson's disease (PD) is a progressive movement disorder and the second most common neurodegenerative disease after Alzheimer's disease. There is no known cure for Parkinson's. However, there are many efforts to improve the quality of life of those affected by Parkinson's. Many domains, such as medical health, nutritional health, functionality, mental health, physical status, self-efficacy, independence, socialization, environment, and spiritual beliefs, are part of quality of life.

Nutrient intake and nutrition status are related to the duration and severity of Parkinson's. Malnutrition, digestion issues, and eating difficulties affect muscle strength, muscle mass, and cramps, affecting balance, which will increase the progression of PD. A poor nutrition status will increase dependency on activities of daily living, thus reducing quality of life.

Aging is a normal phase of the human body, and is characterized by a gradual decline in several systems in vivo. Additionally, people with Parkinson's experience aging and disease progression concurrently. Because of these changes, nutritional needs change according to the patients' symptoms, and some problems may need to be addressed faster than others. When managing an older adult with PD, one must have in mind the regular physiological changes that come with aging and add the physiological changes that develop with PD progression.

Keywords: nutrition, quality of life, Parkinson's, aging

What is Parkinson's disease?

Parkinson's disease (PD) is the second most common neurodegenerative disease after Alzheimer's disease (Braak & Del Tredici-Braak, 2012) with no known cure. PD is a progressive movement disorder characterized by the presence of parkinsonism syndrome (bradykinesia or

tremor, rigidity) and postural instability. However, diagnosis confirmation is completed postmortem via Lewy body presence (aggregates of misfolded α-synuclein protein on neurons) (Braak & Del Tredici-Braak, 2012; Erro & Stamelou, 2017).

Both smooth and skeletal muscle are affected in PD, figure 1 depicts how PD symptoms are related to the type of muscle. The most prominent symptoms of PD are motor symptoms (MS), such as bradykinesia (slowness of movement or reduction in amplitude of movements), tremor of a resting limb, skeletal muscle rigidity (resistance to passive movements), and gait impairments (gait hesitancy or shuffling of feet) (Erro & Stamelou, 2017). People with PD, also, experience between eight to 12 non-motor symptoms (NMS) including: excessive saliva (drooling), change in smell or taste, nausea, constipation, abnormal bowel movements (incontinence), urinary urgency, unexplained pain, weight changes, depression, hallucinations, difficulty concentrating, anxiety, increase or decrease in sex drive, headedness or dizziness (orthostatic hypotension), drowziness, insomnia, vivid dreams, apathy, swelling of legs, and excessive sweating (Rios Romenets et al., 2012; Titova, Qamar, & Chaudhuri, 2017).

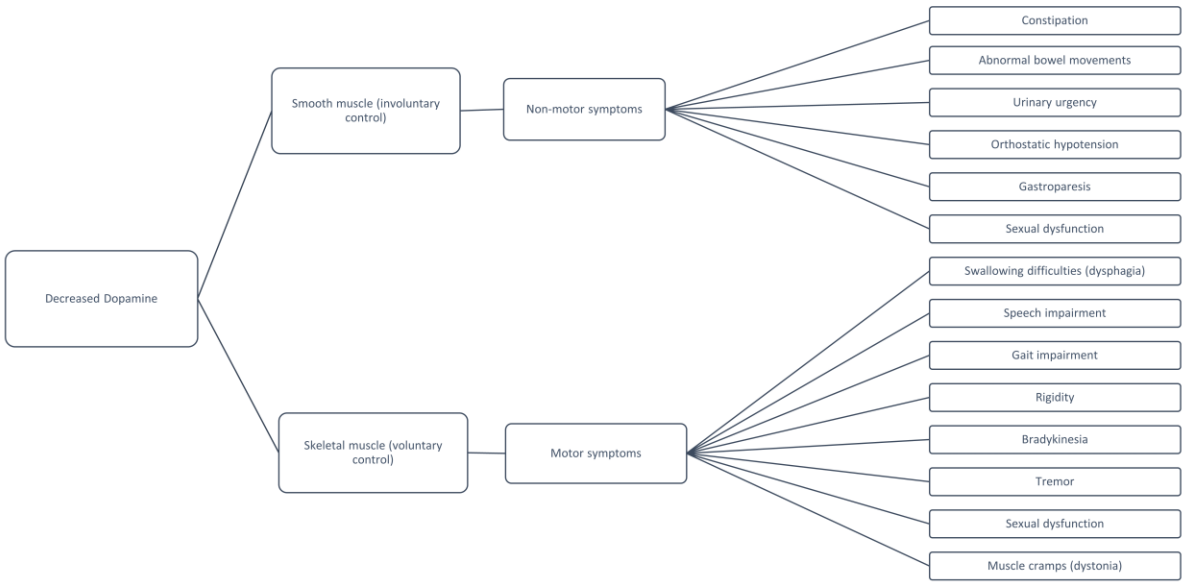
Scientists have two hypotheses as to PD pathology. Some believe that the origin is the central nervous and then moves caudal and others believe that it originates in the peripheral nervous system, the gut, and it moves rostral. Both types might determine different symptoms from patient to patient (Borghammer & Van Den Berge, 2019).

There are no two people with PD that present with exactly the same degree of symptoms. The progression of PD is measured using different rating scales that evaluate MS and NMS. There are five stages of PD progression. During stage one, the person can perform daily activities without any interference (symptoms are mild), such as a slight tremor occurring on one side of the body. Additionally, there are possible changes in facial expression, walking, and

postural stability. In stage two, there is a severity increase of stage one symptoms. Tremor moves to both sides of the body, walking and posture issues are more prominent, and performing activities of daily life become more complex and difficult, but their independence remains. In stage three, this mid-stage is characterized by slowness of movements, balance issues, and falls become common. These significantly impair daily life activities; however, they can still be fully independent. In stage four (4), the severity of the symptoms limits the person from performing activities of daily living on their own, independence is lost, and some assistance for walking may be required (e.g., walker). In stage five (5), leg stiffness is prevalent and significant that the person may not be able to stand or walk. They may be bedridden or in a wheelchair; nursing care is essential for all their activities, and hallucinations may be present (Parkinson's Foundation, n.d.-b).

Figure 1.1.

Decrease in Dopamine Affects Smooth and Skeletal Muscle which Develops in Motor and Non-Motor Symptoms



Quality of life in PD

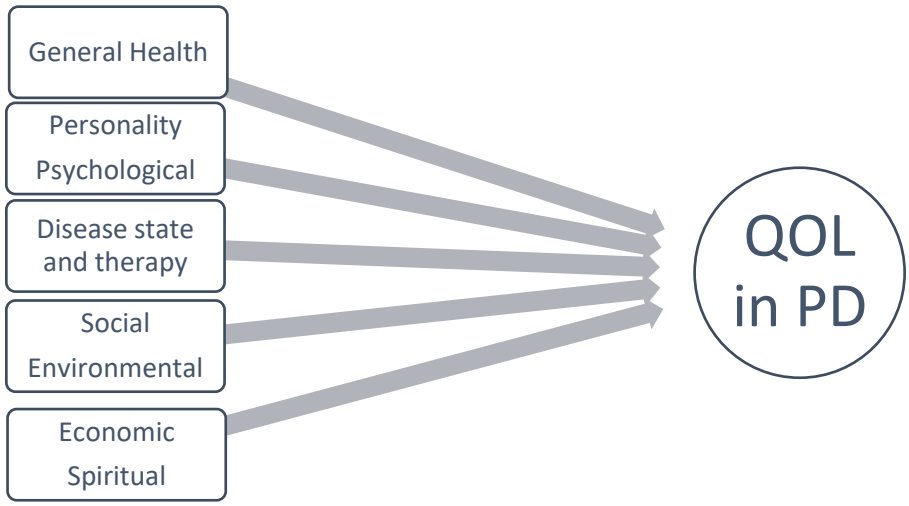
Quality of life (QOL) is subjective to the individual; it encompasses many domains, such as medical health, nutritional health, functionality, mental health, physical status, self-efficacy, independence, socialization, environment, and spiritual beliefs. Additionally, disability, wellness, frailty, and health promotion affects the quality of life (Bernstein & Munoz, 2016a). In Parkinson's disease (PD), as the disease progresses, the likelihood of dependence increases; hence the quality of life may decrease due to decreased functionality. The QOL for people with PD is multifactorial and understanding each domain that surrounds it helps to improve their well-being (Welsh, 2005).

Empowering individuals with PD increases the probabilities of adapting to their disease by enhancing social support, improving self-efficacy, and promoting healthier behaviors (Welsh, 2005). According to Welsh (2005), QOL in PD is influenced by general health, personality

attributes, psychological influences, disease state and therapy, social environments, economy/financial situation, and spiritual beliefs.

Figure 1.2.

Variables Influencing QOL in PD Individuals (Welsh, 2005)



Nutrition plays a modifier role in some of the factors affecting QOL in PD. For example, in general health, individuals with PD may have other comorbid conditions that may increase PD symptoms or interfere with the medication effectiveness. General health includes nutritional state, which increases the progression of PD and disability; it also impacts depression and anxiety (part of psychological influences). The nutritional management of PD is dependent on the treatment and symptoms experienced by the individual. However, if the patient's nutritional status is improved, the non-motor symptoms will be better managed, and the performance of activities of daily living will also be enhanced (Welsh, 2005).

Nutrition in aging and PD

Aging is a normal phase of the human body, and it is characterized by a gradual decline in several systems in our bodies. Aging, by itself, will not lead to disease; however, the physiological changes in aging might lead to an increased likelihood of disease occurrence.

Some of the expected changes in aging are decreases in muscle mass, strength, skeletal mass/density, total body water, total energy expenditure, immune competence, fluid regulation, skin capacity to synthesize vitamin D, kidney function, hormone production, lung elasticity, vasodilatation, and cartilaginous tissue (Bernstein & Munoz, 2016b). Aging, also, increases gastric pH, xerosis, oxidative stress, cognitive impairment, adipose tissue, DNA damage, the incidence of diabetes, gastrointestinal transit time, peripheral vascular resistance, and nutrient requirements (e.g., calcium) (Bernstein & Munoz, 2016b). Many people with PD (PwPD) also experience these changes as a normal part of aging; however, PD exacerbates some of these changes and is an underlying cause of other health conditions.

A search in PubMed using the words "Parkinson's and exercise and motor symptoms" had 1004 results and using the words "Parkinson's and nutrition and non-motor symptoms" had 53 results. The last search had studies pertaining to drug treatments, malnutrition, gut microbiota, vitamins and mineral supplements, weight, and others. A summary of the major nutrition related issues is described below.

Gastrointestinal

Regular aging changes affect the gastrointestinal tract, such as loss of olfactory receptors, decrease in taste buds, delayed stomach emptying, decrease in digestive secretions and enzymes, constipation, and an increase in gastric pH (Bernstein & Munoz, 2016b). In PD, individuals are likely to have greater dental dysfunction due to difficulties in brushing their teeth, pooling of saliva, dry mouth (medication side effect), and jaw rigidity. Dysphagia and gastroparesis are, also, challenges for people with PD since coordination of many muscle movements are required to swallow food and move food throughout the digestive system. Since PD affects neural messaging of smooth muscles, the movements that must occur in the esophagus and intestines,

and the messaging of digestive secretions, becomes impaired or delayed. This intestinal dysmotility increases the likelihood and severity of normal constipation in older adults, making constipation a NM symptom that individuals with PD largely experience. Additionally, people with PD may experience a sense of incomplete evacuation due to anorectal dysfunction (Pfeiffer, 2005).

Gastrointestinal dysfunction may interfere with patient well-being, nutritional balance, and treatment optimization. People with PD experience non-motor symptoms such as constipation, impaired gastric emptying, and small-intestine dysfunction (Barichella, Cereda, & Pezzoli, 2009). Around 50-80% of patients with PD report constipation. Constipation is defined as less than three bowel movements a week and occurs during preclinical and clinical phases of PD and may worsen with disease progression (Verbaan et al., 2007). Constipation might precede motor symptoms by about 20 years, and dehydration or inadequate water intake increases this non-motor symptom (Ueki & Otsuka, 2004). The NPF recommends an intake of fiber of 25-35 grams a day and a proper fluid intake daily. Wheat bran, fruits, vegetables, beans, whole grains are good sources of fiber that help meet this recommendation (NPF, n.d.).

Gut microbiota

Gut microbiota changes according to age, diet, and medications. When the gut microbiota of PD patients was compared to age-match controls, individuals with PD fecal short-chain fatty acids (SCFA) concentration was reduced. Researchers speculate that because SCFA modulates the enteric nervous system, this finding may contribute to gastrointestinal dysmotility due to Lewy bodies' appearance in the neurons that govern the gastrointestinal tract (Unger et al., 2016).

The health of the gut microbiome prevents inflammation and affects the central nervous system. Gut microbiota modulates immune activity, and a high state of inflammation increases neurodegenerative disease progression (Fasano, Visanji, Liu, Lang, & Pfeiffer, 2015). Researchers have found differences in the microbiota of people with PD; these differences suggest that the lack of beneficial bacteria decreases overall well-being and the synthesis of some vitamins (thiamine and folate). The lack of beneficial bacteria leads to gut permeability, increasing inflammation and the accumulation of alpha-synuclein in the enteric nervous system, increasing Parkinson's symptoms and the permeability of environmental toxins (Lange et al., 2019; Scheperjans, Derkinderen, & Borghammer, 2018).

Diet has been shown to regulate gut microbiota and elicit benefits on gastrointestinal dysfunction and medication uptake. A healthier gut may decrease Levodopa dosage and reduce the deposition of alpha-synuclein in the enteric nervous system, potentially slowing PD's progression and the side effects of high doses of Levodopa (Barichella et al., 2019; Perez-Pardo et al., 2017). The NPF recommends a plant-based diet and healthy fats. This diet will emphasize fruits, vegetables, beans, grains, fish, and smaller amounts of meat (NPF, n.d.-a). As one study showed, probiotics decreased constipation where participants had fermented milk products with prebiotic fiber and multiple probiotic strains for four weeks (Barichella et al., 2016). Probiotics are a future research field in PD; and, they influence brain neurochemistry through neurotransmitters' production (Lange et al., 2019).

Body composition and weight changes

Weight and body mass index (BMI) are essential to collect even in early Parkinson's patients. Loss of muscle mass and increase in fat mass are typical features of aging. If left untreated, it will develop into sarcopenia (a combination of loss of muscle mass, muscle

weakness, decrease functional ability leading to disability). Overweight and obesity are concerns of normal aging; however, if unintentional weight loss is present, it is attributed to an underlying disease, including, PD (Bernstein & Munoz, 2016b).

Researchers found changes in Body Mass Index (BMI) are inversely associated with total UPDRS scores (Umehara, Nakahara, Matsuno, Toyoda, & Oka, 2017; A. M. A. Wills et al., 2016). They reported that lower BMI scores are associated with higher (worse) UPDRS scores. Low body weight or low BMI might be associated with a lower density of dopaminergic neurons in PD. Researchers hypothesized that a decrease in adiposity might increase systemic inflammation, which may negatively affect dopaminergic neurons that are already affected by PD progression (Lee et al., 2016). Focusing on body composition as well as BMI might help interventions with PD patients. However, other researchers suggest that BMI is not good enough to classify a person with PD as malnourished because BMI correlates to body fat and not current protein intake. Some patients with PD may not be losing weight but decreasing their protein intake. This reduced intake suggests that the Mini Nutritional Assessment tool (MNA) will help classify malnutrition due to its correlation with protein level according to protein intake (Tomic et al., 2017).

Additionally, subcutaneous fat has been found significantly reduced in PD patients, which increases the ratio of visceral fat to subcutaneous fat, increasing the likelihood of developing metabolic diseases like type 2 diabetes (Bernhardt, Müller, Ludolph, Dupuis, & Kassubek, 2016). These findings suggest PD individuals may present with comorbid conditions that also need to be addressed during nutritional management because their nutritional needs will be determined not only due to PD, but also by other diseases.

Weight changes are a characteristic of NMS in PwPD, and they might be present in the early stages of PD or even before diagnosis. Reduced ability to smell, poor appetite, or abnormal gastrointestinal movement might be factors affecting these weight changes (Mun et al., 2016). Non-motor symptoms of PD, such as taste and olfactory dysfunction, cognitive deficit, mood abnormalities, depression, and food reward alterations, contribute to altering eating patterns and eating pleasure and consequently weight alterations (Aiello, Eleopra, & Rumiati, 2015). Although physiological pathways are not fully understood, weight changes (increase or decrease) in patients with PD should be assessed through multiple lenses. Since it is difficult to determine which PD patients will lose weight during the disease, evaluating other NMS will help with PD management to prevent unintentional weight loss or a low BMI (Sharma & Vassallo, 2014).

Weight loss is not only a characteristic of the progression of PD, but it is also a complex nutritional problem. Difficulty eating and drinking are significantly associated with weight loss (A. M. Wills, Li, Pérez, Ren, & Boyd, 2017). In the early stages of PD or drug-naive PD patients experience loss of smell, poor appetite, and abnormal gastrointestinal movements which influence weight changes (Mun et al., 2016; Tomic et al., 2017). Non-motor symptoms of PD, for example, taste and olfactory dysfunction, cognitive deficit, mood abnormalities, depression, hallucinations, and food reward alterations, contribute to the alteration of eating patterns decreasing eating pleasure and consequently weight alterations (Aiello et al., 2015; Tomic et al., 2017).

Weight loss has repercussions on quality of life measures. Atypical parkinsonism, with sustained significant weight loss, defined as loss of >5% of baseline body weight, increased risk of subsequent dementia, mortality, and dependency (Cumming, Macleod, Myint, & Counsell, 2017). Weight loss was also associated with a greater Hoehn & Yahr stage, a decreased Montreal

Cognitive Assessment (MoCA) score, and increased rate of Levodopa usage, and a greater number of comorbidities (Akbar et al., 2015).

Low body weight or low BMI might be associated with the lower density of nigrostriatal dopaminergic neurons in PD. Some researchers hypothesized that a decrease in adiposity might increase systemic inflammation that will negatively affect dopaminergic neurons affected by the progression of PD (Lee et al., 2016). Furthermore, the depletion of the striatal dopaminergic neurons may negatively influence the neuroendocrine system that regulates nutritional balance and appetite, which could exacerbate undernourishment. Nutritional interventions might correct the systemic conditions that underweight might have on dopaminergic neurons (Lee et al., 2016).

Skeletal changes

Modifying factors like diet, exercise, body weight, hormonal status, and medications influence bone health as we age. Furthermore, the body's vitamin D absorption and synthesis are decreased as a normal part of aging and contribute to skeletal changes (Bernstein & Munoz, 2016b). Individuals with PD are at a significantly higher risk of osteoporosis and osteopenia beyond the normal risk of developing these conditions due to normal aging. When compared to control, PD patients showed a reduced bone mass density. In combination with balance and gait disturbances, skeletal changes elevate the risk of fracture and postural instability in people with PD (Torsney et al., 2014). Levodopa might cause daytime sleepiness, orthostatic hypotension, decreased bone density, and hallucinations. These factors increase the risk of falls and skeletal changes that will change the nutritional needs of PwPD (Torsney et al., 2014). Since PwPD have balance issues, the increased risk of osteoporosis or osteopenia increases the risk of fractures and disability (Torsney et al., 2014).

It is recommended that PwPD be mindful about getting adequate calcium, magnesium, and vitamins D & K. Low consumption of these micronutrients could result from loss of appetite that leads to low consumption of food sources with these micronutrients (Lange, 2019). To meet the requirements of calcium, magnesium, vitamin D & K, PwPD are recommended to consume calcium and vitamin D fortified foods and, if necessary, calcium supplements. One vital aspect of consideration is that protein from dairy may have increased interaction with Levodopa than other proteins (Parkinson's Foundation, n.d.-a). Fortified cereals, fatty fish, liver, and eggs aid in obtaining vitamin D. Broccoli, dark green vegetables, dried beans, peas, and whole grains aid in obtaining magnesium and vitamin K. One hour per week of outdoor activities with the sun reaching face, hands, and arms aids in the synthesis of vitamin D (National, n.d.-b). Furthermore, a high intake of B-vitamins reduces homocysteine levels. Reduction of homocysteine helps decrease dopaminergic cell death, which protects the brain (Lange et al., 2019).

Hydration

As a normal part of aging, the sense of thirst decreases and factors like illness, fever, diarrhea, weather temperature changes, and use of laxatives increase the risk of dehydration (Bernstein & Munoz, 2016b). In PD, the risk of dehydration is even greater due to the regular physiological aging changes, PD medication side effects, lower water intakes, constipation, increased swallowing difficulties, dysphagia, excessive urination, and decreased bladder control. Dehydration increases the risk of aspiration pneumonia, constipation, urinary tract infections, and death. Dehydration leads to mental confusion and exacerbate other PD symptoms like orthostatic hypotension and increased falls (Barichella et al., 2017; Parkinson's Foundation, n.d.-a; Varanese, Birnbaum, Rossi, & Di Rocco, 2010).

Water helps keep stool soft, dissolve vitamins and minerals, prevents urinary tract infections, and provides moisture for dry mouth and eyes (Manz, 2007; National, n.d.-b). In PD, dry mouth and thick saliva is often present due to medication. Therefore, ensuring plenty of fluids is essential to counteract it and prevent bacterial growth and tooth decay (Parkinson's Foundation, n.d.-a). The NPF recommends incorporating fluids gradually to six - eight cups/day, unless there is a preexisting health issue affecting fluid intake.

Nervous system

The number of nerve cells decreases with aging. In PD, this is exacerbated due to the disease progression. In a postmortem study, nerve degeneration was 50% higher in those with PD than controls, meaning that aging does not play a role in PD's neurodegeneration (Scherman et al., 1989).

The nervous system influences the composition and gene expression of gut microbiota Gut microbiota influences the nervous system through the production of neuromodulators, especially in the enteric nervous system. Gut bacteria can produce neurotransmitters such as serotonin, noradrenaline, dopamine, and acetylcholine that influence mood, anxiety, depression, energy, and epigenetics. The structure and diversity of the gut microbiota is vital to assess in PD because its communication with the nervous system may contribute to posture and gait instability (Cenit, Sanz, & Codoñer-Franch, 2017). This bidirectional communication between the brain and the gut may increase neuroinflammation contributing to neural cell death. To prevent neuroinflammation increase, a diet high in antioxidants, fruits, vegetables, whole grains, and polyunsaturated fatty acids is recommended (Uyar & Yildiran, 2019).

Foods for PD

Some researchers have found that intake of fresh fruit and vegetables, nuts, seeds, olive oil, fish (not fried), and fresh herbs and spices might reduce PD progression. However, more processed foods like fried foods, canned food, soda, ice cream, yogurt, beef, and cheese is speculated tohave the opposite effect (Mischley, Lau, & Bennett, 2017). The exposure of neurotoxins through milk has been linked to increased PD risk, but not the disease's progression. Researchers speculate that this might be linked to milk proteins reducing urate levels which is inversely related to PD (Lange et al., 2019).

Omega-3 PUFAs, found in flaxseed, fish oil, fish, nuts and seeds, and polyphenols, found in fruits, vegetables, legumes, spices, and tea, have been studied due to their anti-inflammatory nature. These PUFAs and polyphenols modify brain function and have neuroprotective properties for PD. However, more research needs to be done to measure objective biological markers (Lange et al., 2019).

Distribution of dietary protein

Research suggests that dietary protein may interfere with Levodopa (a drug used to treat Parkinson's disease) by competing for absorption in the intestine and competing for transportation through the blood-brain barrier (Cereda, Barichella, Pedrolli, & Pezzoli, 2010). Protein-medication interaction decreases the effect of Levodopa and increase the 'OFF' periods (when medication is wearing off but the next dose can't be taken yet or it hasn't taken effect, however) and pain (Virmani, Tazan, Mazzoni, Ford, & Greene, 2016).

A protein redistribution diet (PRD) may improve motor symptoms and decrease Levodopa dosage. Researchers suggest an intake of 0.8g/kg of body weight to optimize Levodopa effects. Furthermore, monitoring the PRD is vital to ensure the macro-and

micronutrients are adequate for the patient's daily requirements (Barichella et al., 2017). A critical issue to consider is that some researchers have found that limiting protein in the diet or ingesting protein later in the day (evening meal) might lead to weight loss (Virmani et al., 2016). This protein redistribution decreases weight, and it is detrimental for a person with Parkinson's disease (PD).

To avoid protein-medication interactions, the patient must take Levodopa 20-30 minutes before meals. If the person is experiencing nausea and dizziness, health professionals advised that they take the medication with a low protein food (Cereda et al., 2010)

Diet patterns in PD

The Mediterranean diet (MeDi) emphasizes plenty of fruits and vegetables, nuts, olive oil, legumes, and whole grains. This diet promotes the consumption of seafood, lean meats, and low-fat dairy products. The MeDi diet is low in saturated fat and added sugars and high in polyunsaturated fatty acids and omega-3s (Bernstein & Munoz, 2016a).

In PD, the MeDi has been favorable by protecting against the progression of PD and improving cognitive functions like executive functions, language, memory, and attention. PwPD hasveincreased inflammation in their bodies due to PD, and the MeDi diet is effective in decreasing inflammation by lowering oxidative stress (Lister, 2020; Paknahad, Sheklabadi, Derakhshan, Bagherniya, & Chitsaz, 2020; Stewart, Shamdasani, & Rook, 2007). The MeDi contains antioxidants like vitamin E, vitamin C, and polyphenols. Additionally, this diet is high in folate that regulates the homocysteine levels in the blood. PwPD have more elevated homocysteine levels than usual, which increases the disease's progression (Paknahad et al., 2020). Furthermore, vitamin E improves mitochondrial functions and cognitive performance (Navarro et al., 2005).

The ketogenic diet, a diet high in fats and low in carbohydrates, has also been beneficial for PwPD. In a clinical study, PwPD that followed a ketogenic diet improved motor and non-motor symptoms (VanItallie et al., 2005). However, this diet brings other issues to consider, such as dehydration, constipation, sarcopenia, low appetite, reduced bone density, and increased risk of malnutrition. These are known problems PwPD experience, and the ketogenic diet may add to these non-motor symptoms (Włodarek, 2019).

The Mediterranean-DASH Intervention for Neurological Delay (MIND) diet has gained attention due to its anti-inflammatory nature. The MIND diet consists of a combination of a diet created for hypertension, DASH (Dietary Approaches to Stop Hypertension) diet, and the MeDi. The MIND diet focuses on plenty of fruits and vegetables, whole grains, legumes, and less red meat. The diet concentrates heavily on the inclusion of one serving of leafy greens each day, two or more servings of berries per week, five servings of nuts per week, and four or more servings of beans per week (Academy of Nutrition and Dietetics, 2019).

In Agarwal et al. (2020) cross-sectional study, the MIND diet correlated to a lower PD incidence. The authors concluded that dietary interventions might be an effective tool to delay the onset of PD. Additionally, the MIND diet is rich in antioxidants like vitamin E, vitamin C, folate, carotenoids, and flavonoids, which are associated with slowing the progression of PD (Agarwal, Miller, Yaxley, & Isenring, 2013).

Conclusions

The monitoring of nutritional status is vital for people with PD because it influences motor and non-motor symptoms and slows down or accelerates the disease progression. People with PD's dietary needs are unique to each individual due to changes in motor and non-motor symptoms, medication side effects, response to current treatment, and other possible comorbid

conditions (Cushing, Traviss, & Calne, 2002). Because symptoms vary between individuals with PD and the symptoms progress differently, nutritional and dietary needs likely vary for each patient. Hence, knowing the progression of the disease is crucial to assess the dietary needs of the person. Medication intake and its side effects, energy expenditure, gastrointestinal issues, weight changes, and overall nutritional status need to be assessed to determine specific dietary needs. For example, a person in stage four with a high medication intake may experience hallucinations and nausea, which may decrease food intake, leading to weight loss. A person in stage 1 (recently diagnosed, not taking a high dose of medications) may have weight loss due to a limited food intake due to depression. Both patients are at risk of malnutrition, both have nutritional issues to be addressed, but the nutritional approach will be different due to the causes of low food intake.

In the first stages of PD, patients may experience constipation, lack of sense of smell and taste, and some medication side effects like nausea, dizziness, or hypotension, to mention a few. A more advanced PwPD may still experience the symptoms above but to a chronic or severe degree. As the disease progresses, the side effects of medications such as hallucinations, sleep disturbances, and fatigue may appear or exacerbate due to an increase in medication dosage. There are no precise nutritional changes in each stage of disease progression. It depends on the patient's symptoms, and because there are no two patients alike, it is difficult to tease out what specific nutritional concerns are in each stage. Scientists and clinicians recommend monitoring weight, nausea, dizziness, bowel dysfunction, sleep disturbances, and overall good nutrient intake (e.g., protein intake) at any PD stage (Kuniyoshi & Jankovic, 2005; Leader & Leader, 2009; Tangney, 2019).

Nutrient intake and nutrition status are related to the duration and severity of the motor and non-motor symptoms. Malnutrition, digestion, and eating difficulties affect muscle strength, muscle mass, and cramps, affecting balance, which will increase the progression of PD. Since many of the quality of life features on the questionnaires and scales are based on activities of daily living, a poor nutrition status will decrease independence on these activities, thus reducing quality of life. The lack of mobility that malnutrition causes also affects the person's ability to shop or prepare food. Additionally, the slowness of movement and tremor induced by disease progression causes a feeling of isolation and shame to be seen eating. These issues contribute to inadequate nutrition intake, worsening Parkinson's symptoms, and increasing disease progression. Depression and anxiety create a vicious cycle where lack of nutrient intake increases the progression of PD and depression.

The decrease in nerve cells and specifically dopaminergic neurons are significant because they regulate the enteric and central nervous system, the renal and hormonal system, the muscle movements, and the reward/mood system in humans. Changes in these contribute to lower nutrient intake, constipation, bowel dysfunction, weight changes, and body composition changes. According to each affected area, the nutritional needs may change, and some problems may need to be addressed faster than others. When managing an older adult with PD, one must have in mind the regular physiological changes that come with aging and add the physiological changes that come with PD progression.

Chapter 2 - Components for a successful nutrition education for people with Parkinson's

Abstract

Parkinson's disease (PD) incidence and prevalence are increasing, and it is the second most common neurodegenerative disease worldwide. Parkinson's Disease is progressive and has no known cure. Motor symptoms including slowness of movements (bradykinesia), tremors, rigidity, and gait difficulties are visible movement characteristics of those with PD. People with PD (PwPD), also, suffer from non-motor symptoms that negatively affect their quality of life. Changes in smell or taste sensitivity, nausea, constipation, abnormal bowel movements, urinary urgency, and body weight changes are some of the less apparent significant symptoms, and where nutrition may positively impact patients and their caregivers. All these symptoms decrease the quality of life of those suffering from PD, and indirectly affects their care-partners, too.

The purpose of this review is to discuss nutrition education opportunities for PwPD, and the evidence-based strategies and components for improving their quality of life. There are limited, if any, scientific publications reviewing specific benefits of nutrition education programs in this population. This review discusses the role of focus groups to tailor education programs, the components and factors that increase efficacy of nutrition education programs, and elements of self-management programs that positively impact PwPD.

Focus groups help educators understand what information the target audience wants to learn about and better methods to distribute the information. Successful programs usually have different ways to present the information and use few program objectives. Self-management programs help the participants cope with PD diagnoses and improve communication and mental health. The lack of reporting on nutrition education programs in the scientific community might

be due to little understanding of how nutrition is essential in improving the quality of life of PD patients. Furthermore, existing PD community programs might address nutrition, however, few, if any, collect data to report in peer-review journals.

Keywords: nutrition education, self-management, technology education,

Background

Parkinson's disease (PD) is the second most common neurodegenerative disease after Alzheimer's disease. PD age of onset is typically between 50-65 years of age, and a small percentage have early onset of PD (symptoms begin before age 50) (Ellison, 2020). PD is a progressive neuromuscular disorder where motor symptoms such as bradykinesia (slowness of movement or reduction in amplitude of movements), tremor (on a fully resting limb), rigidity (resistance to passive movements), and gait impairments (gait hesitancy or shuffling of feet) are most prominent (Erro & Stamelou, 2017).

People with PD (PwPD) typically present with between 8-12 non-motor symptoms. Excessive saliva (drooling), change in smell or taste, nausea, abnormal bowel movements (incontinence or constipation), urinary urgency, and weight changes are non-motor symptoms closely related to the patients' nutrition. Other non-motor symptoms include depression, hallucinations, difficulty concentrating, anxiety, increase or decrease in sex drive, light-headiness or dizziness (orthostatic hypotension), difficulty staying awake, insomnia, unexplained pain, vivid dreams, apathy, swelling of legs, and excessive sweating (Rios Romenets et al., 2012; Titova et al., 2017).

Proper education helps patients better manage their non-motor symptoms. Empowering PwPD increases the probabilities of adapting to their disease by enhancing social support, improving self-efficacy, and promoting healthier behaviors (Welsh, 2005). According to Welsh

(2005), general health, personality attributes, psychological influences, disease state and therapy, social environments, financial situation, and spiritual beliefs influence the quality of life in PwPD. One component that modifies these factors is nutrition (Ongun, 2018). The nutritional management of PD is dependent on the current treatment and symptoms experienced by the individual. The nutritional self-management strategies taught to the PwPD improve the nutritional status of the patient and other non-motor symptoms (Ongun, 2018). In that case, the non-motor symptoms will be better managed, and the performance of activities of daily living will also be enhanced, improving overall quality of life (Welsh, 2005). The purpose of this review is to discuss the importance of nutrition education for PwPD, and the evidence-based strategies and components for improving quality of life.

Focus groups to tailor education goals

According to the Medical Subject Headings (MeSH), a focus group is a qualitative data collection method that allows people to interact in a discussion of different topics, opinions, or questions (U.S National Library of Medicine, 2018). Focus groups vary from obtaining general information and generating a hypothesis to stimulating ideas and opinions of a determined theme. Focus groups may help researchers generate data more quickly as compared to completing individual personal interviews, interacting directly with the participant, asking for clarification of opinions, observing non-verbal responses, and/or uncovering new and different data or ideas. Focus group methodology is not without limitations. For example, the information obtained from the participants of focus groups may not be generalizable. The respondents' interaction may generate conflict in the group, and the summarization of data might complicate the analysis of results (Stewart, Shamdasani, & Rook, 2007). However, several interventions using this methodology were successful in determining participants' opinions and needs.

Table 2.1.

Summary of Focus Group Studies and their Outcomes

Study	Sample size (n)	Focus group description	Outcomes
Ashton et al., 2015	61	10 groups of 3-9 people	Physical health, appearance, social influences, and physical performance were primary motivators for healthy eating in a young men population.
Carter et al., 2015	57	-	Mobile dietary assessment tool launch after identifying needs of users.
Haynes-Maslow, Auvergne, Mark, Ammerman, & Weiner, 2015	105	13 groups	Barriers of fruits and vegetables for low-income families are cost, knowledge of cooking, location, freshness, and personal preferences.
Avgerinou et al., 2019	24	Semi-structure interviews	Older adults were unaware of malnutrition risks and lack knowledge on nutritional requirements for older adults.
Karlsson et al., 2015	137	4-10 people per group	Collaboration, communication, and care should be tailored to both the patient and the caregiver to ensure a better team approach.
Cotter, Teixeira, Bontrager, Horton, & Soriano, 2017	28	4 groups of 4-11 people	Enthusiasm about SNAP benefits to buy fresh produce at local farmers' markets.
Wolfson, Bleich, Smith, & Frattaroli, 2016	53	7 groups	The meaning of cooking is not an universal definition independent of income.
Marrone et al., 2017	76	8 groups	People with hearing loss concerns have concerns about cost, stigma, low self-esteem, lack of resources, and low self-efficacy.
Pino, Boulay, Jouen, & Rigaud, 2015	25	1 group of 7 people	Caregivers supported a robot's idea to help them with caregiving duties to decrease their burden.

Motivators and barriers of a population are crucial to understanding which healthy/lifestyle interventions are more likely to translate. For example, young men in Australia reported, through focus groups, improvement of physical health, appearance, social influences, and physical performance were their primary motivators for healthy eating. Opposite to this finding, this group reported time, cost, social interactions, and scheduling tasks as barriers to healthy eating. Furthermore, a busy lifestyle, logistic factors (cost), cognitive-emotional factors (i.e., self-consciousness), and social factors (i.e., group memberships) were barriers to physical activity. Research to unveil personal motivators and barriers towards healthy lifestyles is crucial for developing interventions that will engage the target group (Ashton et al., 2015).

Focus groups help identify individuals' perceptions. A study in North Carolina identified cost, knowledge of cooking, location, freshness, and personal preferences as some of the barriers to accessing fruits and vegetables by low-income families. In this study, participants of focus groups also proposed ideas on overcoming some of the barriers affecting access to fruits and vegetables. This study's authors advise engaging community members when implementing well-being strategies; focus groups helped them understand the community's interests and barriers in community interventions (Haynes-Maslow, Auvergne, Mark, Ammerman, & Weiner, 2015).

Focus groups are useful to understand attitudes towards specific topics. Focus groups conducted in Washington DC demonstrated that low-income adults in urban and affordable housing communities wanted access to healthy foods at a limited cost. They were enthusiastic about using SNAP benefits to buy fresh produce at local farmers' markets and had interested in participating in nutrition education programs. This research also showed a lack of understanding on how to use SNAP benefits outside of traditional grocery stores and how to use other programs

for low-income households to acquire sustenance (Cotter, Teixeira, Bontrager, Horton, & Soriano, 2017).

In Europe, focus groups helped determine a better approach to treat those with dementia. Researchers concluded that focusing on both the caregiver and the person with dementia was the better approach to treat this ailment. According to the participants' answers, collaboration, communication, and care should be tailored to both the patient and the caregiver to ensure a better team approach to treat these patients (Karlsson et al., 2015).

To gather information about new products or therapies, focus groups are considered an effective assessment tool. For example, an online 24-h dietary assessment tool was tested in the United Kingdom in different age groups. Researchers used focus groups to identify user needs, ease of navigation, visual design opinions, and essential features the program should have to make the user feel comfortable. This study resulted in the launch of a dietary assessment tool that was better accepted by users (Carter et al., 2015).

A study done by Wolfson and colleagues found, using focus groups, that the meaning of cooking is not a universal definition independent of income. Individuals from low and high-income neighborhoods reported that organizing, planning, and enjoyment were key facilitators of cooking. Both low-income and high-income communities perceived cost as a barrier. However, low-income participants were concerned about the affordability of food as a whole, and high-income participants were worried about the cost of trading regular food items for organic produce or hormone-free meat. Based on their focus groups data, the authors concluded that the meaning of cooking is heterogeneous and that public health messages need to account for different perspectives in a community (Wolfson, Bleich, Smith, & Frattaroli, 2016)

Researchers in rural Arizona identified cost, stigma, low self-esteem, lack of resources, and low self-efficacy as personal hearing loss concerns. The authors used the Health Belief Model's constructs to tailor an educational program to this community's unmet needs using focus groups. Due to the focus groups' answers, the authors shifted their plan to be a self-management program instead of acknowledging hearing loss in the community (Marrone et al., 2017). Constructs of behavioral theories are useful in focus groups to increase understanding of the community or participants' needs and strengths. Marrone et al. (2017) also concluded that by engaging partners and community members, educational programs will potentially be culturally and linguistically appropriate to meet their individuals' needs.

Marrone and colleagues also used focus groups to evaluate their education program. They found that self-efficacy increased after describing their experiences and modeling and mastering factors that led to self-efficacy. This interaction is difficult to determine in a written survey, but focus groups are a way to evaluate behavior and self-efficacy toward a specific theme.

A study by Avgerinou and colleagues reported that some older adults are unaware of malnutrition risks; however, they are open to clinicians' dietary advice. After conducting semi-structure interviews on 24 older adults (>75 years old) in London, researchers found that most participants reported a lower quality food intake and a low appetite contributing to malnutrition. Participants demonstrated a lack of knowledge on nutritional requirements for older adults. Still, carers used meal preparation strategies and changing eating utensils to help the person they cared for. In conclusion, this study demonstrated an unawareness about proper nutrition for older adults. This finding is a starting point for training primary care professionals and support older adults' nutritional care (Avgerinou et al., 2019).

Companies developing new technologies are also using focus groups to address acceptance by customers. A study focused on understanding patients' preferences for robots providing their care demonstrated customer interest in appearance and personalization; however, a robot with a humanoid appearance was not well received by some participants. Participants in this study were: (1) people with mild cognitive impairment, (2) healthy older adults, and (3) caregivers of people with Dementia. This last group expressed concern about the usability of this robot for someone with Dementia. They argued that even if a person in the early stages of Dementia is taught how to use the robot, they might forget how to use it later. Additionally, caregivers supported a robot's idea to help them with caregiving duties to decrease their burden. Authors concluded that for older adults, the concept of using robots for care is not unimaginable, but to fully develop the technology and understand how to implement more research needs to happen (Pino, Boulay, Jouen, & Rigaud, 2015).

Nutrition education for behavior change

According to Contento (2008), "any combination of educational strategies, accompanied by environmental supports, designed to facilitate voluntary adoption of food choices and other food and nutrition-related behaviors conducive to health and well-being" is, in essence, what nutrition education is (Contento, 2008).

In Murimi and colleagues' (2017) systematic review, it was reported that for a nutrition education program to be effective, the intervention duration was found to be essential. Other crucial factors included focusing on few objectives, appropriate use of behavior theories, and management support. The most robust interventions are the ones that are randomized control trials, and those interventions with a duration of more than five months report higher levels of success. Interventions with three or less clearly defined and measurable objectives were

successful even though the interventions' duration was less than six months. In this systematic review, studies that used a theory as a base successfully achieved their primary objectives. Work setting interventions are less successful if they lack support from management and/or collaborators (Murimi et al., 2017).

The Texas Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) created a client-centered nutrition education program. This program's features included clients choosing the classes they had interested in, different formats to present the information (group classes, take-home, or online lessons), and foreign languages. Additionally, communication with staff and other health care centers was successful, educational materials changed continuously to adapt to the client's needs, and instructors had guidelines on conducting the sessions. This program allowed other local agencies to collaborate to have a voice in developing this client-centered program and the co-creation of educational material (Isbell, Seth, Atwood, & Ray, 2015). Institutional or management support help by providing a path for collaboration among local agencies for educational program development.

Fruit and vegetable consumption increased in a group of men and women after a 10-week nutrition education program. Researchers allocated 54 participants, with a BMI equal or greater of 25 kg/m2, into three groups (1) control, (2) education with provision of fruits and vegetables, and (3) education only groups. The Health Believe Model was the base of this program. Participants in both education groups reported an increase in the consumption frequency of fruits and vegetables high in antioxidants like vitamin C, beta carotene, zeaxanthin, and lutein. The intervention made emphasis on replacing energy-dense and nutrient-poor foods with fruits and vegetables. Statistics between the two education groups were not significant; both groups increased consumption of fruits and vegetables after the nutrition education program. Programs

aimed at improving the intake of fruits and vegetables decrease obesity risk in a population (Wagner, Rhee, Honrath, Blodgett Salafia, & Terbizan, 2016).

A nutrition education-based cooking program in Canada, increased nutrition, health, and disease knowledge among a community of adults 50 years old and older. Participants of this Canadian program increased their confidence in healthier meals and had desired behavior changes. This 8-week program, for adults 50 years of age and older, focused on improving food skills and knowledge by using hands-on activities and self-regulatory behaviors (i.e., food preparation) to improve self-efficacy. However, researchers were surprised that, despite the behavior changes, participants didn't increase autonomy in preparing and eating nutritious food. A possible explanation is that they already had a high autonomy level (Moreau, Plourde, Hendrickson-Nelson, & Martin, 2015). In the United States, home-delivered nutrition programs, federally and privately funded, help older adults have various nutritious foods that help those with minimal cooking skills. Additionally, congregate meals help those who feel lonely; as loneliness, in many cases, causes a low intake of nutritious meals. Participants of these programs also receive nutrition education and counseling to promote healthier behaviors and avoid disease complications (Lloyd & Wellman, 2015).

Mobile technologies keep proliferating to provide users better experiences. Among thousands of apps offered daily, the mobile health (mHealth) apps have been a topic of discussion on the effects they have on health-related behavior change. mHealth apps vary significantly from the user-friendly interface, the database used, and the information provided (Hingle & Patrick, 2016). Apps developed by academics are usually the least liked by users; these apps depend on grant funding, making it difficult to maintain over time and fix errors. Many commercial health apps focus heavily on weight loss (leaving aside chronic conditions)

and lack evidence-based information; however, users prefer these apps over the academically developed ones. If a mHealth app's goal is to measure behavior change, it is essential to consider the point of interest and the user's primary goal. For clinicians, a mHealth app has the potential to help predict a health outcome; for success, tracking, self-monitoring, and goal setting are important features the app should have. The use of mHealth for research is possible but is not without its limitations (Hingle & Patrick, 2016).

For nutrition education via an electronic device, such as a smartphone, the length of information provided (e.g., videos), context, logistics, and interaction (e.g., a practice learned skills) are important aspects to maximize the effectiveness of behavior change. The Expanded Food and Nutrition Education Program (EFNEP) developed an eLearning program called Food eTalk. This program was designed for participants to have a resource available for when they were making nutrition-related choices. eTalk was based on the Health Belief Model and had interactive learning games, short lessons, and a southern influence (e.g., southern recipes). Classes were 8-12 minutes long and included cooking videos. Programs like this required more personnel than a face-to-face program due to logistics and communication with other community stakeholders. This extensive development team works with experts in nutrition and videographers, photographers, and more, adds to the budget of these types of programs (Stotz & Lee, 2018). Electronic learning programs are potentially useful to provide instruction to participants and encourage a behavior change.

Combining traditional face-to-face programs with technology has proven to increase self-efficacy and nutrition knowledge among middle-aged and older adults in Taiwan. Researchers incorporated touch-screen devices with lectures on health education. The program lasted six weeks. This combination improved learning outcomes. Researchers speculated that the success

might have been because people have diverse abilities and learning styles and this program catered to those. Participants reported that this combination was exciting and motivating because it involved all their senses (Chiu, Kuo, & Dai-Chan, 2019).

Nutrition education for health care workers has also been successful in increasing nutrition knowledge. In a study in Australia, midwives and nurses received nutrition education face-to-face or online. Both modalities received positive comments, and participants improved nutrition knowledge and confidence in advising pregnant women about nutrition. The completion rate for both modalities was 36%; time constraints and servers blocking learning platforms were two of the main reasons for this result. However, the online program participants expressed that videos were the most valuable piece of information in the program (Lucas et al., 2019). Nutrition education led by dietitians, using evidence-based data, successfully improved patient care by training the trainer.

Stanford University found that massive open online courses (MOOC) promotes healthier behaviors like healthy eating and nutritional meal composition. This MOOC of the Stanford Child Nutrition and Cooking, released in February 2014 through Coursera, had 7,422 participants who completed the entire course (including pre-and post-test). This free program had five weeks of instructional and cooking videos and the Social Cognitive Theory base. This program was the first international public health intervention that improved participants' eating behaviors and meal composition/preparation. Participants who were overweight or obese seemed to have benefited from this program because they had significant improvements in their consumption of fruits and vegetables. Researchers advise on tailoring messaging for sub-populations to accomplish a more significant impact. MOOCs' nature allows participants to

become involved in nutrition education beyond traditional forms, making this strategy worthy and useful for those with logistical barriers (Adam, Young-Wolff, Konar, & Winkleby, 2015).

Intake of fruits and vegetables in a population helps decrease the risk of chronic conditions. Many countries have addressed a low intake of fruits and vegetables through nutrition education programs to change people's behaviors worldwide. A nutrition education program's success depends on many variables such as duration, design, theoretical base, validity and reliability, and intervention power. However, using people's food preferences, perceptions, beliefs, attitudes, and meaning, along with environmental factors, helps the success of these programs. Understanding possible barriers of the program help to account for possible solutions (Pem & Jeewon, 2015).

Self-management programs in PD

There was not a publication that evaluated nutrition education in PD. Even though Parkinson's programs worldwide might have nutrition lessons, they do not report it in the scientific community. The most applicable programs found were generated self-management programs designed to help patients better manage their disease to improve their quality of life, without the capacity to isolate nutrition components.

Self-regulation consists of observing own behavior, comparing it to a standard desirable action, and evaluating it to make future changes. During self-regulation, the person moves resources and skills to reach a desirable and measurable goal. Self-regulation helps the patient, family members, and healthcare professionals provide quality care (K. D. Lyons, 2004).

Table 2.2.

Summary of Components for Successful Educational Programs

Components that can make a nutrition education program successful:	• Duration of education sessions and program as a whole • Number of objectives, a few goals have better success • Appropriate behavior change theory • Local agencies collaboration • Client-centered education • Information presented in different formats and languages • Combination of face-to-face instruction with technology • Communication with healthcare workers in the community • Consideration of environmental factors • Consideration of food preferences, perceptions, beliefs, attitudes, and meanings • Incorporation of self-management strategies (e.g., goal setting, mindfulness, self-care) • Designing a user-friendly program that is easy to navigate (for online programs) • Consideration of which staff is essential in the creating and implementation of the program
Components that can make a self-management program successful:	• Teach management of disease symptoms and medications • Help participants to self-observe their behavior to propose future changes • Teach how to move resources to cope • Teach communication strategies • Teach self-monitoring techniques • Include care partners • Teach self-caring skills • Incorporate mental health • Promote awareness of patterns • Develop care networks

According to a systematic review on self-management programs for PwPD, seven main components stood out: medication management, exercise, self-monitoring techniques, psychological strategies, maintenance of independence, social engagements, and providing knowledge. Authors advise for the inclusion of these components in self-management programs

for PwPD to increase care effectiveness. For PwPD, specific self-management strategies combined with information and knowledge helps motivation to achieve goals (Tuijt et al., 2020).

Living with Parkinson's is not an easy task; the progression of symptoms negatively impacts the patient and the care partner (Mosley, Moodie, & Dissanayaka, 2017). Parkinson's education groups need to include the care partners because they are indirectly affected by PD. Self-management programs help people advocate for themselves, increase their confidence, and take charge of their condition (K. S. Lyons et al., 2020), whether participants are PwPD or care-partners.

In Australia, a self-management program explored the mindfulness component as a positive self-management strategy that could alleviate anxiety and stress associated with PD. This 6-week-long program, with 2 hours/week of mindfulness sessions, helped their participants to improve their control perception, understanding of the disease, and social interactions. Authors used the ESSENCE model in their program, which stands for education, stress-management, spirituality, exercise, nutrition, connectedness, and environment (Vandenberg et al., 2019).

The pilot self-management program, Strive to Thrive in Oregon (U.S.), improved skills and knowledge on health behaviors of people with PD and their care partners. Spouses included in this program increased their mental relaxation and decreased their depressive symptoms. Couples were more communicative about themselves (e.g., worries/concerns) than controls. This dynamic led to positive communication behaviors and better management of the disease (K. S. Lyons et al., 2020).

The Swedish National Parkinson School, in 2015, developed a national patient education and self-management model for PwPD, which included care partners as well. This program

focused on the disease as well as living with it. It taught participants self-monitoring skills and promoted awareness of thoughts, feelings, and actions. The Swedish National Parkinson School taught PwPD and their care partners to self-observe their symptoms and intake of medicine, participate in self-care activities that promoted feelings of well-being and happiness, and manage PD's emotional impact. This program shed light on improving the health status of PwPD by teaching them to self-manage their condition (Hellqvist, Berterö, Dizdar, Sund-Levander, & Hagell, 2020).

The Sweden National Parkinson School found self-management programs' skills to be successful and sustained after the program. Participants were evaluated 3 to 15 months after the program; researchers found that participants were using the skills taught. Researchers concluded that their self-management program could help PwPD and their care-partners to engage in skills that help handle PD's physical and psychological symptoms by increasing self-efficacy (Hellqvist, Berterö, Hagell, Dizdar, & Sund-Levander, 2020).

Health care workers benefit from self-management programs because the communication between patients and healthcare workers is enhanced. Researchers in Germany reviewed all self-management structures for PwPD in their country; they did not find any formal structure to support a robust program like the Swedish National Parkinson School had implemented. Their goal is to provide equal, timely, and better quality care to PwPD by replicating a person-centered self-management program like Sweden (Tennigkeit et al., 2020).

Self-management skills, like behavior change, medication adherence, exercise, diet, the environmental organization, and motor and non-motors symptoms management, depend on many factors. A Korean cross-sectional study (n=356) found that social support, self-efficacy, education, religion, income, and non-motor symptoms influence self-management in PwPD.

Researchers found a negative correlation between non-motor symptoms (like mood/cognition, urinary and gastrointestinal issues, sleep/fatigue problems, and attention/memory difficulties) with self-management skills. There was no correlation between PD duration and self-management skills (Lim et al., 2020).

One-on-one self-management education and other health education have proven to be a useful tool for PwPD in Canada. This 6-month, pre-post design program recruited 100 participants who received patient-centered, integrated, self-management support, and technology-enabled care. Researchers concluded that the development and implementation of care networks are useful to close the gap between healthcare facilities and communities/homes. Furthermore, this and similar programs have a sustainable cost and decrease healthcare expenses (Mestre et al., 2020).

Whether is individual-self-guided or group self-management programs, they both have the potential to improve depression in PD. Sajatovic and colleagues compared both individual-self-guided and group exercise programs with a self-management component. They found that depression improved in both groups with no significant differences between the groups. In the group sessions, participants stated that meeting others was important, and researchers speculate that peer education and support are of value in these programs (Sajatovic et al., 2017).

Conclusions

Nutrition potentially improves many of the non-motor symptoms of PD. To our knowledge, there is not a peer-review publication that addresses nutrition education programs in PD. The lack of reporting on nutrition education programs in the scientific community might be due to little understanding of how nutrition is essential in improving the quality of life of PD

patients. Community programs in PD may address this topic but might not report it. Some of these PD community programs might incorporate cooking lessons or a few nutrition talks a year.

Furthermore, many of these nutrition education lessons might not produce enough data to qualify for a peer-review journal, or there might not be an interest in contributing to the scientific community. In the future, to develop a nutrition education program that suits PwPD's needs is crucial to conduct an assessment to determine which topics are of interest and which method of delivery is suitable. Focus groups are an excellent method to determine needs and the best education method. Self-management programs are also great to use as examples of strategies that work and structure a successful program. In conclusion, successful educational programs have few goals, teach participants self-regulation, present information in different formats, and adapt to their needs.

Additionally, support from an established organization seems to increase the impact of educational programs. This review didn't find any peer-review publication about nutrition education in PD, but it sheds light on how other programs have created successful behavior changes benefiting quality of life.

For PD, nutrition education is essential to alleviate some of the non-motor symptoms like constipation, medication side effect, digestive irregularities, dehydration, bone thinning, and weight changes (Parkinson’s Foundation, n.d.-a). Non-motor symptoms may be debilitating for both the PwPD and their care-partner. Knowing about basic nutrition and how some food combinations can help slow down the progression of PD is of value for this population. In the PD treatment, nutrition education seems to take a back seat, but in combination with current medical treatments, the PwPD and their care-partner can have better outcomes to improve their quality of life.

Chapter 3 - Virtual nutrition education for Parkinson's disease: A pilot study

Background

After Alzheimer's disease, Parkinson's disease (PD) is the most common neurodegenerative disease. Parkinson's disease is a neurologic disorder marked by parkinsonism syndrome (bradykinesia or tremor, rigidity, and postural instability) (Braak & Del Tredici-Braak, 2012).

As the disease progresses, the probability of dependency increases. Thus, quality of life eventually suffers as a result of decreased functionality. Some of the factors influencing quality of life (QOL) in people with PD are affected by nutrition. Malnutrition, digestive problems, and eating difficulties impair muscle strength, mass, and cramps, reducing balance and speeding up the development of (Welsh, 2005).

Quality of life is subjective to the individual; it encompasses many domains, such as medical health, nutritional health, functionality, mental health, physical status, self-efficacy, independence, socialization, environment, and spiritual beliefs (Bernstein & Munoz, 2016a).

Individuals with PD may present with comorbid conditions that exacerbate PD symptoms and/or interfere with medication efficacy. Nutritional status affects the progression of PD, risk of disability, incidence of depression, and occurrence of anxiety (part of psychological influences). The individual's treatment plan and symptoms determine the dietary management of PD. When the patient's nutritional status improves, their non-motor symptoms (NMS) tend to be better controlled, and activities of daily living will be enhanced too (Welsh, 2005).

Patient well-being, nutrient bioavailability, and treatment optimization are impacted by the onset of gastrointestinal dysfunction. The most common gastrointestinal NMS in PwPD are: constipation, delayed gastric emptying, and small-intestine dysfunction (Barichella et al., 2009).

Nutrition concerns in Parkinson's disease

Gut health

Constipation affects 50-80% of people with Parkinson's disease. Researchers discovered differences in the microbiota of people with Parkinson's disease, implying that a lack of beneficial bacteria reduces overall well-being and vitamin synthesis (thiamine and folate). The lack of beneficial bacteria cause gut permeability, which increases inflammation and alpha-synuclein accumulation in the enteric nervous system, worsening Parkinson's symptoms and making environmental toxins more permeable (Lange et al., 2019; Scheperjans et al., 2018). In the general population, research about the use of probiotics to treat constipation demonstrates that not all probiotic strains exhibit beneficial effects to decrease constipation (Dimidi, Mark Scott, & Whelan, 2020).

Diet has the potential to regulate gut microbiota, which can help with gastrointestinal problems and drug absorption. A healthier gut may reduce Levodopa dosage (a drug used to manage PD) and alpha-synuclein deposition in the enteric nervous system, potentially slowing the progression of PD and decreasing the side effects of high Levodopa doses (Barichella et al., 2019; Perez-Pardo et al., 2017).

Body composition

Weight change is part of NMS in people with PD (PwPD), and this can occur early in the disease or even before diagnosis. These weight changes may be caused by a loss of smell, a lack of appetite, or abnormal bowel movement (Mun et al., 2016). Taste and olfactory disturbance,

cognitive deficit, mood abnormalities, depression, and changes in food reward all lead to changes in eating habits and eating satisfaction, as well as weight changes (Aiello et al., 2015). A higher Hoehn & Yahr stage, a lower cognitive assessment, a higher rate of Levodopa use, and a higher number of comorbidities have all been linked to weight loss in PwPD (Akbar et al., 2015). Depletion of striatal dopaminergic neurons can have a detrimental impact on the neuroendocrine system, which controls nutritional balance and appetite, potentially leading to increased malnutrition (Lee et al., 2016).

Osteoporosis

Individuals with PD have a much greater risk of developing osteoporosis and osteopenia. Patients with PD had lower bone mass density than controls, a study found (Torsney et al., 2014). Hormonal changes place females at an increased risk. Additionally, skeletal alterations, when combined with balance and gait abnormalities, increase the risk of fracture and postural instability in people with Parkinson's disease (Torsney et al., 2014).

Daytime sleepiness, orthostatic hypotension, decreased bone density, and hallucinations are possible side effects of Levodopa. These factors raise the risk of falls and skeletal alterations, which will alter PwPD's nutritional requirements (Torsney et al., 2014). The risk of falls and hip fracture is affected by nocturia (waking up one or more times at night to urinate), which PwPD report as bothersome (Batla, Phé, De Min, & Panicker, 2016).

Dehydration

Fluid intake in PwPD varies greatly (300-1100 ml/day) (Cassani et al., 2017; Ueki & Otsuka, 2004) and dehydration is more likely to occur because of physiological aging changes (decrease sense of thirst), drug side effects, swallowing problems, dysphagia, excessive urination, and seasonal temperature changes. Aspiration pneumonia, constipation, urinary tract

infections, and death are all increased by dehydration (Parkinson's Foundation, n.d.-a; Varanese et al., 2010).

Swallowing difficulties and nocturia negatively affect QoL in PwPD. In a swallowing study, PwPD had worse scores for the eating duration, communication, fatigue, and fear than controls (Carneiro et al., 2014). Even though some PwPD consider it normal waking up at night to urinate, it is unpleasant for many. It is recommended that the PwPD reduce fluids and large meals a few hours before bed (Batla et al., 2016). This recommendation needs to be taken with caution to prevent dehydration due to excessive reduced fluid intake. Additionally, PwPD are encouraged to exercise as part of their therapy. During exercise, body temperature increases, and sweat is produced. Sweat increases the risk of dehydration (fluid loss through the skin) if fluids are not appropriately replenished before, during, and after exercise (Medeiros & Wildman, 2012). Water loss related to exercise is important to account for in PwPD.

Protein

According to research, dietary protein interferes with the absorption of Levodopa by competing for absorption in the intestine and transportation through the blood-brain barrier (Cereda et al., 2010). Protein-medication interactions reduce Levodopa's effect and increase OFF periods (when medication is wearing off, but the next dose can't be taken or hasn't taken effect) and pain (Virmani et al., 2016).

The PwPD must ingest Levodopa 20-30 minutes before meals to prevent protein-medication interactions. If there are feelings of nausea and dizziness, it is recommended to take the drug with a low-protein meal/foods (Cereda et al., 2010). To maximize Levodopa effects, researchers recommend consuming 0.8g/kg of body weight a day to avoid medication dose

increases. An increase of 10g of protein increases Levodopa dose by 0.7 mg/kg/day (Barichella et al., 2017)

The purpose of this study was to develop, implement, and evaluate a virtual nutrition education program for PwPD and their care-partners that addresses common nutritional concerns in PD.

Methodology

Aim

This study aimed to increase nutrition knowledge and improve quality of life through virtual nutrition education to PwPD and their care-partners.

Design

This experimental design was a mixed-methods approach, using focus groups to determine topics of interest and pre-and post-self-report data to assess program effectiveness and quality of life.

Participants

A total of 21 people participated in the focus groups and 28 people (including 17 participants of the focus group) in total enrolled in the program. The average age was 67 years old, and only 2 of them were care-partners. The participants were recruited by contacting ambassadors from the Davis Phinney Foundation. Ambassadors sent the recruitment flyer to different educational and support Parkinson's groups in the United States (US). Participants' inclusion criteria were diagnosis of Parkinson's disease and ability to complete online surveys. Care-partner inclusion criteria were to be caring for someone with a diagnosis of Parkinson's disease. PwPD participated in the focus group via Zoom -a videoconferencing platform- due to the COVID-19 restrictions from June to December 2020.

The focus group's questions were (1) how many of you have thought about the foods we eat and the effect on Parkinson's? How do you feel about the interaction between the foods you eat and Parkinson's disease? Do you think there is an effect? (2) Where do you get information about nutrition education and Parkinson's? (3) How do you feel about the resources available regarding nutrition education for those affected by Parkinson's? (4) What would you benefit the most from a nutrition education program on Parkinson's disease? (5) What topics would you consider important to cover in a nutrition education program on Parkinson's disease? What is your preferred learning style?

The previous questions were established by following the format provided by David W. Steward in his book "Focus groups" ((Stewart et al., 2007). Focus groups interview questions were created to guide the participant from a broad to a specific view surrounding the topic around nutrition in PD. The questions followed the format following format: (1) fewer than 12 questions, (2) relative unstructured question using "how do you feel about", "do you think", "what do you think about", and (3) avoiding 'yes' or 'no' answers.

The focus groups' information was transcribed and grouped by each main question using the scissor-and-sort technique. This technique focuses on major topics and issues and 'cut-and-paste' words, sentences, or phrases from the transcribed focus groups (Stewart et al., 2007). Data were analyzed for major themes and nutrition topics of interest to determine the nutrition education sessions' topics. Grouping of the participants answers into common themes used to develop the modules can be found in table 3-1. Full analysis of the focus groups answers can be found in appendix A. The program lasted eight weeks total; six out of eight weeks was nutrition education. The program was self-paced and online to conform with COVID-19 restrictions in 2020.

Table 3.1.

Classification of Participant's Comments by Common Themes

Themes	
Healthy eating	• "I try to eat more vegetables and fruits and nuts, since I got diagnosed, I try to watch more what I eat." • "I want to stay healthy and I figured good foods are better for you." • "I think in general being a good diet is good for everything so it must be good for Parkinson too." • "I think we are all encouraged to eat healthy you know so here I am wanting to eat healthy." • "Some of the medications can cause compulsive Behavior one of them is compulsive eating so that can be an issue with Parkinson's also." • "How bad are certain things, I mean you got to live." • "There are ads that people fall into for example supplements vs no supplements, how much is enough, what's legitimate what's approved what approval matters?" • "I know that foods that are not processed are better foods for you. What are good carbs and bad carbs I'm learning the names and kind of the things to look for again." • "How to read the food label, people need to know if you go to the grocery store you read the label and you see these five ingredients in the label then put it down don't buy it so I think like shopping, make some cooking classes."
Protein and Levodopa	• "I'm trying to find out information about the effect of eating protein and how it may affect my meds. So many different answers on the topic and I'm somewhat lost looking for an answer." • "Eating protein when you have your levodopa whether it is before or after how long 30 minutes an hour." •

Table 3.1. *Classification of Participant's Comments by Common Themes (Continuation)*

Themes	
Protein and Levodopa	• "The biggest interaction I think about is the relationship between protein Sinemet and Carbidopa levodopa and I'm supposed to wait a certain amount of time to eat protein before after I take it." • "I've Heard lots of things particularly about protein and the effect it has on levodopa." • "Sometimes protein affects the medicine." • "I don't pay attention to the protein to be honest with you, I eat so much meat that it will be tough to avoid." • "The relationship to protein approaching so 30 to 60 minutes before or after the med you don't eat foods with protein, so you time your drugs around it or around drugs." • "I have known for quite some time that protein would compete with my Sinemet for access."
Foods to eat vs foods to avoid	• "I will benefit from nutrition to improve my quality of life It will be better for me." • "The types of food you should have versus the types and you shouldn't." • "Come up with like if I eat like this or don't eat this before bedtime or do you eat before bedtime this may or may not help." • "Anything to specifically avoid, that research shows that is disadvantageous for Parkinson's Disease." • "Things that people with Parkinson's shouldn't be eating. I know we usually have gut issues. I'd like to know if there is anything that you absolutely shouldn't do nutritionally if you have Parkinson's."
Timing of foods and medication	• "Timing and medication related to food intake." • "Is that more beneficial than having the main meal at five or six."
Constipation/Upset stomach	• "with Parkinson's constipation is an issue." • "The constipation I think it's real and what works for one person may not work for somebody else and so it will be nice to hear what some options are." • "PA [physician assistant] gave me two items to look for in probiotics and since I switched to that probiotic things have been much better." •

Table 3.1. *Classification of Participant's Comments by Common Themes (Continuation)*

Themes	
Constipation/Upset stomach	• "I think that it would be valuable for every person now that has Parkinson's if they just had a regular gut movement it would be huge." • "My medication makes me constipated so what I have tried to do is eat more food that has fiber in it. This on my own part because I still have to take MiraLAX to help with it. I don't want to take it so I do try to eat you know healthier and it's still ahh it's it is what it is." • "I love my cheese; however, constipation also runs pretty strong and a lot of Parkinson patients, so I had to back off a little bit on that." "My Sinemet really upsets my stomach."
Hydration	"What kind of tea is best for you; which ones are hoaxes and they really don't do anything for you?"
Inflammation/gut	• "Inflammation" • "I want to fix everything I can fix without a pill and then go from there You know if I can fix my Gut and not take a stool softener and a probiotic and Miralax that will be fantastic." • "I guess probiotics too will be something I'm interested to and what type of probiotics do you need." • "I really feel strongly there is an inflammation issue in my body and so my goal is to eat food that it's the least inflammatory as possible and so I try to avoid dairy." • "It really feels like the gut-brain connection in Parkinson's is really critical and the second brain the gut." • Parkinson gut Theory really struck home another area that for the landscape seems to be evolving is again back to the gut prebiotics vs. probiotics." • "But a lot of the probiotics it seemed to be most effective come from fermented foods but with one of my Parkinson's medicine I take I'm told that you don't you can't have too many fermented foods because it can affect the efficacy of the medication so I feel like it's this vicious circle."

Program design

The Self-Determination Theory was used to develop the program. This theory focuses on human motivation and personality. The Self-Determination theory's primary constructs are autonomy, competence, and relatedness; it guides the person through different motivation stages to accomplish a goal (Center for self-determination theory, 2021).

The study's nutrition education portion was divided into six modules: 'basic nutrition,' 'healthy eating,' 'PD and the gut,' 'inflammation and PD,' 'constipation and hydration,' and 'protein and Levodopa.' Each module had objectives that defined the material covered in the videos. Each module had two lesson videos of content with a duration of 5-15 minutes. Handouts about the video lessons were available for participants. A video and written recipe was included to promote healthy foods, healthy preparations, and examples of the video lessons' topics. Participants had access to a discussion board to comment on their achievements or doubts, as well as a handout to set specific, measurable, achievable, relevant, and time-bound (SMART) goals. The instructor encouraged participants to set goals for the modules and share them with the rest of the participants. At the end of each module and throughout the handouts, participants were encouraged to keep learning about nutrition to become self-advocates.

Handout's layout was adapted from the Nutrition & Activity for Communities program from Kansas State Research and Extension office (Kansas State University Extension Food, Nutrition, 2020). Each handout had an objectives section, a small summary of the main topic of that module, and the information explained in the videos. Pictures were used to exemplify the information. Some information was in bold letters to attract reader's attention to the most essential information, such as examples of foods with saturated fats or how micronutrients help

the body. Every module handout had references to convey credibility and provide the reader with more resources to research.

Figure 3.1.

Example of Handout Used in the Online Program

Lesson 1 - Basic Nutrition, Micronutrients

Objectives of the lesson

- Understand what are micronutrients
- Understand what micronutrients are critical for Parkisnon's

Micronutrients

Micronutrients are what we often call **vitamins and minerals.** There are approximately 30 vitamins and minerals that our bodies cannot produce on its own so that if why we need to consume them in our diets.

Functions of micronutrients

- Help prevent diseases
- Help lower inflammation
- If we don't get enough and we have a deficiency it can lead to chronic conditions or increase the progression of pre-existing conditions
- Maintain immune function and help us fight viruses and bacteria.

What micronutrients are critical in Parkinson's?

Folate helps **preserve memory**, helps form DNA, and helps **break down homocysteine**. High level of homocysteine can lead to vascular disease and dementia in general, it damages DNA, causes a toxicity in the body, and adds to the normal oxidative stress in the body. You can find this micronutrient in **dark-leafy greens, beans, lentils, nuts, and peanuts.**

Vitamin B6 helps **support the immune system and brains health** and as folate, it helps maintain normal levels of homocysteine. This vitamin also **helps to form neurotransmitters** like serotonin (one of the mood hormones). You can find vitamin B6 in **beef liver, tuna, salmon, fortified cereals, poultry, dark-leafy greens, bananas, papaya, oranges, and cantaloupe.**

Vitamin B12 helps delay the onset of dementia and helps in mental function and neuron development. This vitamin is needed to **form red blood cells and DNA** also. This vitamin can be found in **fish, red meat, eggs, poultry, dairy, and fortified cereals.**

Calcium and vitamin D help with bone health and since people with Parkinson's are at increased rick of bone loss, these two micronutrients are essential to incorporate in the diet. Additionally, research has found that people with Parkinson's have decreased blood levels of vitamin D and it can be detrimental for bone health. Some sources of **calcium are tofu, almond milk, nonfat milk, cheese, yogurt, spinach, sardines, beans, and collard greens** (like broccoli, kale, swiss chard, and cabbage). Some sources of **vitamin D are salmon, sardines, egg yolk, fortified cereals, fortified orange juice, fortified plant milk, and dairy products.**

For the recipes, a handout was created that provided the ingredients and the instructions to follow. At the end of each handout was a note that provided a little information of the benefits

found in the finished product, for example, “this recipe is a good source of fiber,” indicating that the final food product is a good source of fiber. In each video recipe, there was an explanation of each ingredient’s benefit to help reinforce the content in the video modules.

Figure 3.2.

Example of Recipe Handout Used in the Online Program

The goal-setting handout was created with a brief description of what the SMART acronym means and an example on how to use. There was a check the box chart to help participants follow-up their goals and evaluate themselves. All handouts can be found in appendix B.

For module six, two extra handouts were created. One with high and low protein foods and a second one to schedule meals and medications. For the high and low protein foods, examples of food item, serving size, and amount of protein per serving was provided. There were three classifications, foods high in protein, foods low in protein, and plant foods high in protein.

An email was sent out at the beginning of the week to remind participants about the program. Each module had a welcome video where the instructor talked about the topic for that week, answered questions from the previous week, and commented on goal progress. Additionally, at the end of the module, participants were provided a test to assess knowledge.

This program is similar to a Massive Open Online Course (MOOC). MOOCs usually have 5-10 minutes length videos, students can access the resources in their own time, and their duration is between five to sixteen weeks (Baturay, 2015). MOOC participants report high dropout (90%) rates due to lack of time, lack of interaction, insufficient skills, and personal reasons (Gütl, Rizzardini, Chang, & Morales, 2014). A six-week period for this program was chosen to prevent high dropout rates.

Module development

According to comments such as “I want to stay healthy and I figured good foods are better for you,” “what are good carbs and bad carbs I'm learning the names and kind of the things to look for again,” and “the types of food you should have versus the types and you shouldn't,” reflect a need for basic nutrition understanding that serves as a starting point to address more complex nutrition issues in PD. Modules one and two were created to address this lack of basic

nutrition knowledge. Participants were eager to know what foods were better or worse for PD. This was included in the basic nutrition modules as well.

Module one objectives

- Understand the different functions of the macronutrients and micronutrients
- Identify foods that contain protein, healthy and unhealthy fats, and whole grains
- Identify one goal or action to introduce healthy fats or whole grains

Module two objectives

- Understand the different functions of the macronutrients
- Identify foods that contain protein, healthy and unhealthy fats, and whole grains
- Identify one goal or action to introduce healthy fats or whole grains
- Understand how to read a food label
- Understand the ingredients list

Comments such as “I know we usually have gut issues. I'd like to know if there is anything that you absolutely shouldn't do nutritionally if you have Parkinson's,” “I want to fix everything I can fix without a pill and then go from there you know if I can fix my gut and not take a stool softener and a probiotic and Miralax that will be fantastic,” and “I really feel strongly there is an inflammation issue in my body and so my goal is to eat food that it's the least inflammatory as possible and so I try to avoid dairy” reflect a need to understand gut health and how to improve inflammation. Modules three and four were created to help the participant understand what influences the gut and how they can take steps towards a better gut health.

Module three objectives

- Understand how the gut influences the nervous system
- Understand the hypothesis about how PD originated in the gut
- Understand what gut microbiota is
- Understand foods and behaviors that will help gut health.

Module four objectives

- Understand how gut permeability affect PWPD
- Understand what causes systemic inflammation
- Understand what foods can help decrease inflammation
- Understand what foods can help decrease inflammation

According to the literature, constipation is a prominent digestive issue in PD. The participants from the focus group showed interest in this topic with comments such as “with Parkinson's constipation is an issue,” “the constipation I think it's real and what works for one person may not work for somebody else and so it will be nice to hear what some options are,” and “my medication makes me constipated so what I have tried to do is eat more food that has fiber in it.” Module five was design to help the participant understand how nutrition can help aid constipation and how different foods and hydration can help with this digestive issue.

Module five objectives

- Understand how nutrition can help constipation
- Understand the difference between soluble and insoluble fiber
- Understand why hydration is important
- Identify foods that can aid in constipation

Protein-Levodopa interaction has been reported in previous literature, however, when participants were asked about this topic some were not fully aware that high protein foods can decrease PD medication effectiveness. This is evidenced in comments such as “I'm trying to find out information about the effect of eating protein and how it may affect my meds. So many different answers on the topic and I'm somewhat lost looking for an answer,” and “I've heard lots of things particularly about protein and the effect it has on levodopa.” Module six was created to explain the food-medication interaction and help participants to make a plan on how to time their meals according to their medication schedule.

Module six objective

- Review protein functions
- Remember the sources of protein
- Understand the interaction between protein and medication
- Understand how to time protein and medication

Data collection

In week one and week eight, participants answered the following questionnaires:

(1) Demographics and other health-related information (medications, bowel movements, physical activity, program involvement). The Bowel Health – BHQ: SPs 20+ questionnaire

from the National Health and Nutrition Examination Survey was included in this questionnaire (Rockwood et al., 2000).

(2) Diet History Questionnaire (DHQ3) from the National Cancer Institute (Subar et al., 2001).

(3) Mini Nutritional Assessment (MNA) (Kaiser et al., 2009).

(4) Parkinson's disease quality of life measured (PDQ-39) (only person with PD) (Jenkinson, Fitzpatrick, Peto, Greenhall, & Hyman, 1997).

(5) Unified Parkinson's Disease Rating Scale (UPDRS) (except part III) (Martinez-Martin et al., 2013).

(6) CHAMPS activities questionnaire for older adults (Feldman et al., 2009).

(7) Motivation inventory adapted from the Treatment Self-Regulation Questionnaire (TSRQ) (Levesque et al., 2007).

(8) Nutrition knowledge questionnaire based on the information provided in the program;

(9) Program evaluation (only in week 8). The Intrinsic Motivation Inventory (IMI) was adapted for the educational program for the program evaluation (Markland & Hardy, 1997). The IMI adaptation score ranges from 0=not at all to 7=very true. Additionally, there was a second program evaluation to inquire about the helpfulness of the program. This second evaluation score ranges from 1= strongly disagree to 5=strongly agree. Open-ended questions were included to inquire about any changes post-intervention, the program's importance, and helpfulness.

Data analysis

Focus groups were transcribed and analyzed for common themes by the researcher. Data gathered from all questionnaires and surveys was analyzed and reported using descriptive statistics. T-tests were performed to determine significant differences between before and after

the program. Bonferroni correction was calculated for the DHQ-3 and PDQ-39. The non-parametric counterpart of the t-test, the Wilcoxon signed rank test, was performed to determine significance in a small sample size before and after treatment due to the skewness of the data. Microsoft Excel © was used for data analysis.

Ethical considerations

Ethical approval for this study was obtained by the Kansas State University Institutional Review Board (IRB) in May 2020.

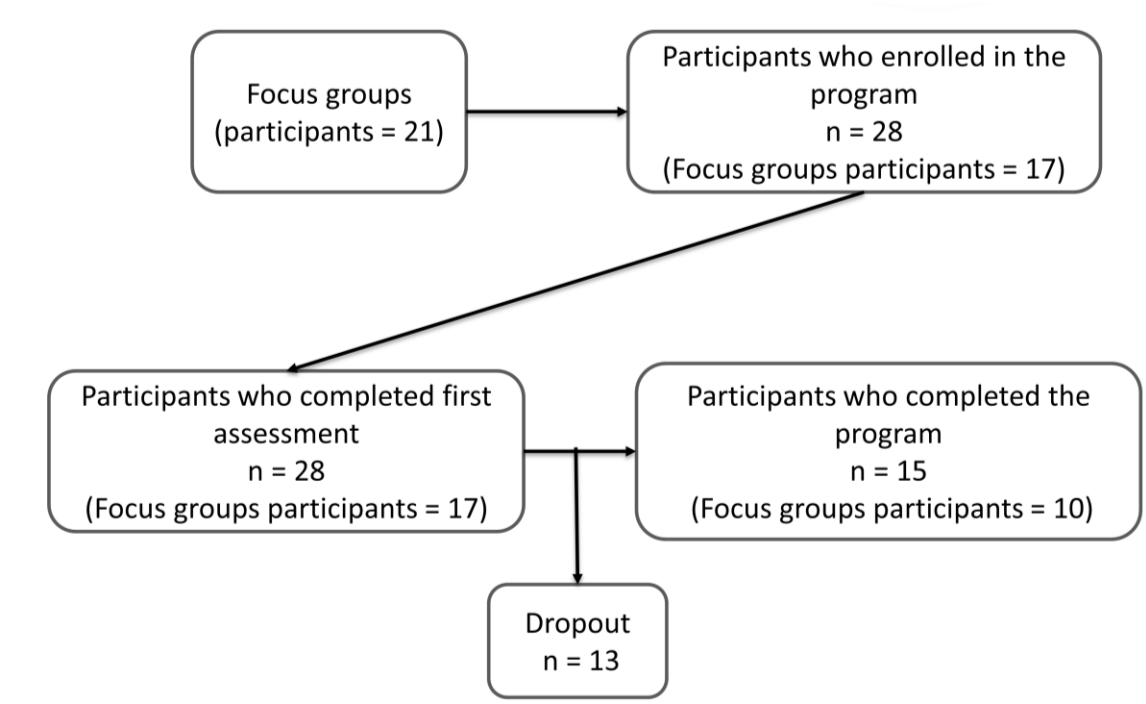
Results

Participants' characteristics

A total of 28 people enrolled in the virtual program (17 of these participants also participated in the focus groups), and fifteen participants (including ten participants from the focus group stage) completed the pre-and post-surveys (54% completion rate). The mean age was 69 (range 53-89 years), and more females (n=9) than males (n=6) participated. Most of them had a college degree or higher (n=14) and lived at home with family (n=14). Participants had an average of 4.68 (±1.04) years living with the diagnoses of PD. Seven of them were involved in support groups; five were engaged in an exercise group (e.g., boxing, yoga, standing exercises). One was involved in a speech class, and one was involved in a PD monthly educational meeting.

Figure 3.3.

Flow Chart of Participants Recruited and Dropped Out



Pre- and post-survey

Participants filled out pre-and post-questionnaires about quality of life, nutritional status, and the UPDRS. Higher scores for these questionnaires indicate a worse patient state. For the quality of life measure (PDQ-39) (n=12), malnutrition risk (n=11), and the UPDRS (n=13), no significant difference was found before and after the intervention. Mobility, emotional well-being, social support, and cognition domains from the PDQ-39 scores decreased post-intervention, indicating an increase in quality of life in these four domains. According to the MNA average score, participants are at risk of malnutrition, one participant changed from risk of malnutrition to malnourished, and another changed from normal nutritional status to risk of malnutrition after the intervention.

Not all domains of the UPDRS scale were completed (part III-Motor symptoms was left out), but scores on the completed domains indicated no significant change in the progression of PD during the program. The score for the UPDRS was assessed by adding the score of each chosen answer by the participant. Since part III of the scale was left out, no overall score is reported.

Before the intervention, fourteen participants (93%) reported bowel movements every day; after the intervention, all participants reported bowel movements at least once a day, no significant difference was found between pre-and post-reports. More than half of the participants reported constant constipation issues in a month period before and after the intervention. Pre- and post-intervention, eight participants reported using laxatives in the last 30 days.

Motivation about nutrition knowledge (n=5) increased after intervention, but no significant difference was found. Participants burn out could have been an influencer on the low response for this survey. Participants also increased their nutrition knowledge from 52.80 (±16.18) to 66.20 (±6.34). Individuals reported an average of 10.86 (±13.62) hours of exercise-related activities a week before intervention and 9.80 (±13.13) post-intervention.

Table 3.2.

Participants Pre- and Post-Questionnaires Averages

Variable	Pre ± SD	Post ± SD	p-value
Quality of life score (PDQ-39) n=12			
Mobility	12.5±24.0	11.5±19.6	0.6
Activities of daily living	12.2±19.5	12.5±16.3	0.9
Emotional well-being	16.3±15.4	15.3±13.2	0.5
Stigma	12.5±15.1	12.5±16.4	1.0
Social support	4.9±9.0	3.5±6.6	0.6
Cognition	17.4±11.0	16.3±11.4	0.6
Communication	9.0±10.3	12.5±16.1	0.2
Bodily discomfort	30.6±17.9	30.6±14.4	1.0
Total average score	14.4±10.0	14.3±9.4	0.9
MNA score n=13	11.3±0.4	10.5±0.6	0.2
UPDRS n=13	18.5±3.2	16.2±3.4	0.1
Nutrition motivation score n=5	104.4±10.2	106.6±4.5	0.2
Frequency, number of participants who experienced different bowel movements per day (n=15)			
1 per day	10	11	
2 per day	1	2	
3 per day	2	2	
4 per day	1	0	
0 per week	1	0	
Average bowel movements per day	1.5±1.1	1.4±0.7	0.8
Frequency, number of participants who experienced constipation a month (n=15)			
Most of the time	5	5	
Sometimes	3	4	
Rarely	5	3	
Never	2	3	
Average time participants experience constipation	3=sometimes	3=sometimes	1.00

Table 3.2. *Participants Pre- and Post-Questionnaires Averages (Continuation)*

Variable	Pre ± SD	Post ± SD	p-value
Frequency, number of participants who used laxatives in the last 30 days (n=15)			
Yes	8	8	1.0
No	7	7	1.0
Nutrition knowledge test score (n=5)	52.8±16.2	66.2±6.3	0.2
CHAMPS, duration (hours/week) in all exercise related activities (n=13)	10.9±13.6	9.8±13.1	0.2

Note. Bonferroni correction for PDQ-39 was p<0.006.

Table 3.3.

Participants Averages of Macro- and Micronutrients Intake

Variable	Pre ± SD	Post ± SD	p-value
DHQ-3 (n=10)			
Kcal/day	1697.1±804.5	1756.9 ±731.0	0.6
Total protein (g)	57.9±19.7	64.3±33.9	0.3
Total carbohydrates (g)	213.6±109.6	214.0±79.5	1.0
Added sugars (g)	51.9±54.7	52.3±50.4	1.0
Fiber (g)	21.8±8.1	23.6±8.6	0.2
Total fat (g)	67.6±37.0	74.3±37.8	0.3
Saturated (g)	21.9 ±16.4	23.6±15.9	0.4
Monosaturated (g)	24.6 ±12.6	27.7±13.5	0.3
Polyunsaturated (g)	15.26 ±7.6	16.7±7.7	0.4
Vitamin A (mcg)	3535.5±2451.0	3918.9±3387.9	0.5
Vitamin E (mcg)	9.1 ±4.3	11.0±5.1	0.2
Vitamin D (mcg)	4.2 ±2.6	5.0±3.2	0.1
Vitamin C (mg)	96.2 ±73.1	110.4±84.2	0.2
Vitamin B12 (mcg)	3.7±1.8	3.4±1.4	0.3
Folate (mcg)	351.3 ±134.2	403.6±180.9	0.1
Calcium (mg)	750.3 ±256.3	803.1±340.8	0.4
Magnesium (mg)	298.4 ±99.3	341.7±143.3	0.1
Omega-3 (g)	1.7 ±1.2	1.8±1.4	0.4
Water (g)	2903.4 ±1137.0	3364.7±2830.1	0.5
HEI-2015 Score	68.4±12.3	69.3±13.8	0.5

Note. Bonferroni correction for kcal, macro- and micronutrients was p<0.002.

Participant's Average of Food Groups Intake Per Day

Table 3.4.

Participant's Average of Food Groups Intake Per Day

Food group	Pre ± SD	Post ± SD	p-value
Total fruit (cups)	1.9±1.2	2.0±1.1	0.7
Dark-green vegetable (cups)	0.5±0.4	0.7±0.7	0.2
Total vegetable (cups)	1.7±1.0	1.9±1.4	0.6
Legumes vegetable (cups)	0.1±0.1	0.1±0.1	0.7
Whole grain (oz)	1.0±0.5	1.1±0.6	0.5
Refined grain (oz)	3.7±2.7	3.3±2.2	0.4
Total meat, poultry, seafood protein foods (oz)	2.8±1.8	3.1±2.5	0.5
Nuts and seeds protein foods (oz)	0.9±0.5	1.8±1.2	0.1
Total protein foods (oz)	4.2±2.0	5.4±3.7	0.2
Total dairy (cups)	1.0±0.6	1.1±0.8	0.5

Note. Bonferroni correction for food groups intake per day was $p<0.005$.

Ten participants completed the pre-and-post DHQ-3, magnesium intake was the only nutrient to increase numerically and had statistical significance ($p<0.05$) before Bonferroni. After calculating the Bonferroni correction ($p<0.002$) magnesium dietary increase was not statistically significant. Participants also reported increased consumption of total calories, protein, carbohydrates, fats, micronutrients, and minerals in the post-assessment. Post-assessment, participants are over the Dietary Reference Intake (DRI) (Institute of Medicine (US) Committee to Review Dietary Reference Intakes for Vitamin D and Calcium, 2011) for total protein (>51g/day), total carbohydrates (>130g/day), vitamin A (>800 mcg/day), vitamin C (>82.5 mg/day), folate (>400 mcg/day), and water (>3200 g/day). Additionally, vitamin E (<15 mcg/day), vitamin D (<10 mcg/day), calcium (<1100 mg/day), magnesium (<380 mg/day), and fiber (<25 g/day) post-assessment intake was below the recommendation. The comparison was made using the DRI average for men and women 51-70 years of age. The healthy eating index was also higher in the post-assessment which is higher than the average index for Americans 65+ years old.

There was an increase in most food groups, fruits, dark-green vegetables, total vegetables, whole grains, total meat, poultry, seafood protein foods, nuts and seeds, and dairy (table 3-4). Participants decreased intake of refined grains and consumption of legumes remained almost the same.

Table 3.5.

Results From the Wilcoxon Signed Rank Test

Variable	Critical value	Wilcoxon test value
Quality of life score (PDQ-39) (n=12)	13	32
MNA score (n=13)	17	8*
UPDRS (n=13)	17	19
Nutrition motivation score (n=5)	0	5
Bowel movements per day (n=15)	25	5*
Frequency of constipation a month (n=15)	25	2*
HEI-2015 Score (n=10)	8	20
Nutrition knowledge test score (n=5)	Data unavailable	0

Note. The asterisk symbol (*) indicates a significant difference.

After the virtual program, six out of 12 participants (50%) improve their quality of life. Only one participant reported a decrease in their nutrition motivation score and obtained the exact score in the nutrition knowledge test. Six participants (60%) reported an improvement in their HEI-2015, indicating a better eating pattern.

After treatment, the score for the MNA increased significantly, indicating worse nutritional status. Four participants (31%) had no change in their nutritional status, five participants (38%) had a worsening in their nutritional status, and four participants (31%) had an improvement. According to the Wilcoxon Signed Rank test, there is a significant decrease in nutritional status.

Ten participants (67%) reported no change in bowel movements per day and only three participants (20%) reported fewer bowel movements per day, and two participants (13%) reported an increase. According to the Wilcoxon Signed Rank test, there is significantly less bowel movement a day after treatment.

Eleven participants (74%) had no change in frequency of constipation, two participants (13%) had an increase in the frequency of constipation, and two participants (2%) had a decrease. This finding was significant according to the Wilcoxon Signed Rank test. However, according to the data, determining if the change was positive or negative is impossible because the number of participants who had changes in constipation is the same.

Program evaluation

Participants who answered the IMI adaptation (n=4) had high interest and enjoyment (6.4±0.6) in the program, had a medium to high perceived competency (5.9±0.4), and their reported effort was high (6.1±0.5). Participants also reported medium pressure while doing the program, a high choice while completing the program, and a medium to high value of the program's usefulness. Overall, the participant's intrinsic motivation was medium, with an average score across all domains of 5.7 (±1.2). Due to the length of all the surveys in this study, participants might have skipped this survey due to time constraints, even though multiple follow-up email reminders were sent after completing the program.

Table 3.6.

Average Scores of IMI Adaptation Questionnaire (n=4)

Interest/Enjoyment domain	Mean	± SD
I enjoyed doing this program very much	6.8	0.5
This program was fun to do.	6.8	0.5
I thought this was a boring program (r)	6.8	0.5
I would describe this program as very interesting.	6.8	0.5
This program did not hold my attention at all. (r)	6.5	0.6
I thought this program was quite enjoyable.	6.5	0.6
While I was doing this program, I was thinking about how much I enjoyed it.	5.0	2.8
Total domain score	**6.4**	**0.6**

Table 3.6. *Average Scores of IMI Adaptation Questionnaire (n=4) (Continuation)*

Perceived Competence domain	Mean	± SD
I am satisfied with my performance at this program.	6.3	1.0
This was a program that I couldn't do very well. (r)	6.3	1.5
I was pretty skilled at this program.	5.8	0.5
I think I am pretty good at this program.	5.5	1.0
After working at this program for awhile, I felt pretty competent.	5.5	1.0
Total domain score	**5.9**	**0.4**
Effort/Importance domain		
I didn't try very hard to do well at this program. (r)	6.5	0.6
I didn't put much energy into this program. (r)	6.5	0.6
It was important to me to do well at this program.	6.3	0.5
I tried very hard on this program.	5.5	1.0
I put a lot of effort into this program.	5.5	0.6
Total domain score	**6.1**	**0.5**
I felt very tense while doing this program.	6.3	1.5
I was very relaxed in doing this program. (r)	6.3	1.5
I did not feel nervous at all while doing this program.	6.0	1.4
I was anxious while working on this program.	1.3	0.5
I felt pressured while doing this program.	1.8	1.5
Total domain score	**4.3**	**2.6**
Perceived Choice domain		
I didn't really have a choice about doing this program. (r)	7.0	0.0
I did this program because I had no choice. (r)	7.0	0.0
I did this program because I wanted to.	7.0	0.0
I believe I had some choice about doing this program.	6.8	0.5
I did this program because I had to. (r)	6.3	1.5
I felt like I had to do this program. (r)	4.3	3.2
I felt like it was not my own choice to do this program. (r)	4.0	3.5
Total domain score	**6.0**	**1.3**

Table 3.6. *Average Scores of IMI Adaptation Questionnaire (n=4)*

Value/Usefulness domain	Mean	± SD
I believe this program was of some value to me.	6.5	0.6
I believe doing this program was beneficial to me.	6.5	0.6
I think this program was an important activity.	6.5	0.6
I would be willing to do this program again because it had some value to me.	3.0	2.5
Total domain score	**5.6**	**1.8**
Total score for full evaluation instrument	**5.7**	**1.2**

Note. The symbol (r) indicates a reversed question, score was adjusted to match the rest of the scores. A higher score represents a positive outcome. Scores range from 1-7 points, 1 indicates low, 3.5 indicates medium, 7 indicates high.

For the virtual program's helpfulness (n=13), overall, participants rated the program at 4.3 (±0.5), indicating they agree the program was helpful. Participants agreed that this program was relevant, engaging, worthwhile, easy to use, helped them learn, and was appealing. Furthermore, participants agreed that the program covered the topics they wanted to know; it was easy to understand and easy to navigate. They also would recommend this program to other PwPD and care-partners. Participants also agree that the objectives of each module were achieved.

Table 3.7.

Average Scores Reported for the Helpfulness of the Program (n=13)

Questions	**Mean**	**± SD**
The modules had the right amount of information	4.8	0.4
The overall design of the modules was appealing	4.7	0.6
Overall, the program held my interest	4.6	0.6
Overall, the program was worthwhile	4.6	0.7
The modules were easy to use	4.6	0.9
Overall, the program was relevant for me	4.5	0.9
The information in the program was easy to understand	4.5	0.8
The handouts of the videos helped me learn	4.4	0.8
The length of the modules was just right	4.4	0.8

Table 3.7. *Average Scores Reported for the Helpfulness the Program (n=13) (Continuation)*

Questions	**Mean**	**± SD**
The program covered the topics I wanted to learn about	4.4	0.8
Would you recommend this program to other people with PD or care-partners?	4.4	0.8
The video lessons helped me learn	4.3	0.7
Do you feel that your participation in the nutrition program will have a positive impact on your journey with Parkinson's?	4.2	0.9
This nutrition program led me to feel more motivated to improve my nutrition	4.2	0.8
The information in the program provided new ideas to me	4.2	0.8
Would you participate in an advanced nutrition program on a specialty topic or another nutrition program in the future as a refresher?	4.1	0.8
The module quizzes helped me learn	4.1	0.9
I've put into practice some of the information I learned in the program	3.9	1.0
Do you feel that you will meet some or all of the goals that you set for yourself in this program?	3.9	0.7
The recipes in the program were useful to me	3.4	1.1
I've shared some of the information I learned in the program with someone else	3.2	1.4
I've tried to make some of the recipes from the program	2.6	0.9
Objectives achieved		
The objectives for module 1 were achieved	4.7	0.6
The objectives for module 2 were achieved	4.7	0.5
The objectives for module 5 were achieved	4.6	0.7
The objectives for module 4 were achieved	4.6	0.7
The objectives for module 3 were achieved	4.6	0.7
The objectives for module 4 were achieved	4.5	0.8
Total score	**4.3**	**0.5**

Ten participants reported this virtual program led them to have more awareness of 'healthy eating for PD.' Eleven reported more awareness in 'gut health for PD' and 'more foods to help their gut health." Nine reported more awareness in 'protein and Levodopa interaction.' Eight participants reported increased awareness on constipation, hydration, and eating healthy for PD. Six participants reported increased awareness in timing protein-medication and changing their hydration strategy.

Table 3.8.

Participants Increased Awareness Topics (n=13)

Question	Number of people who chose the topic
Has this nutrition program led you to have more awareness in	
Gut health for PD	11
Include more foods to help your gut health	11
Healthy eating for PD	10
Protein and Levodopa interaction	9
Constipation and hydration in PD	8
Has this nutrition program led you to make changes in the following areas (select all that apply)	
Eating healthy for PD	8
Timing protein and Levodopa medication	6
Change your hydration strategy to help with constipation and normal hydration	6
Include more fiber to aid constipation	5

Some participants think this virtual program will "help newly diagnosed persons and those beginning use of carbidopa-levodopa" and also it "help understand the importance of good nutrition." Some also expressed that this virtual program helped them to "gain more understanding of food," "get inspired to use good nutrition," and "think more about the food I

eat." This virtual program led participants to "pay attention to prebiotics and probiotics," "be more conscious of what I eat," "more careful med timing," "included more fiber, and good fats - more salmon and fish," "try to reduce sweets and eat more vegetables," "learned about ways to improve my diet," "include fermented foods in diet daily. Increasing fresh fruits and vegetables", "include more vegetables," "drink more water, nuts, greens and fruits," and "checking labels."

Participants also expressed some recommendations to improve the program including "make clear the differences in terminology between food industry definitions and biochemical definitions. Fats vs lipids, macromolecules vs small molecules for example", "maybe a pre-study survey to determine current levels of knowledge," "make the printable handouts to be in outline form because takes up too much ink or send out a booklet," "give students, in advance, a realistic time estimate to complete the entire class, including the surveys, BEFORE they embark on the program," and "more recipes and some meal planning."

Discussion

This pilot study aimed to increase nutrition knowledge and improve the QOL of PwPD. Care-partners were included in this study because previous self-management programs suggested that the inclusion of care-partners enhanced the positive outcomes on the PwPD (K. D. Lyons, 2004; K. S. Lyons et al., 2020). Most of the participants had a high educational level which may indicate a higher socioeconomic status that allows them to purchase more specialty foods or have higher access to electronic devices to complete the virtual program. Most of them assisted to some social group (e.g., exercise, boxing, yoga, support group). This outcome helps PwPD socialize through these groups to decrease isolation and improve QOL by helping with self-identity and autonomy (Bognar et al., 2017).

The average score for the MNA indicated a risk of malnutrition documented in previous literature and continues to be an essential element to include in the treatment of PwPD (Włodarek, 2019). Even though there was no significant difference in QOL before or after the intervention, participants' comments about how this virtual program helped them could have

contributed to a better outcome in emotional well-being and social support domains from the PDQ-39.

Because the program was of short duration (6 weeks of content), results from the UPDRS scale were not expected to change significantly. Estimates suggest that changes in UPDRS scores are noticeable in a period of one to five years (Holden, Finseth, Sillau, & Berman, 2017). Changes in UPDRS scores can be observed from one to five years on average This measure was used as a control of PD progression. Furthermore, despite a significant decrease in bowel movements a day and significant change in constipation, participants did express how the program led them to be more aware of gut health and strategies to stay hydrated to reduce constipation. Constipation is still a topic that most PwPD are interested in due to its high prevalence (Lange et al., 2019; Scheperjans et al., 2018).

Due to COVID-19, some participants expressed via email that their results on the DHQ-3 were not realistic because they could not go to the supermarket or buy their regular food items. COVID-19 related changes in dietary patterns (lack of access to fruits, vegetables, and whole grains) and exercise could be one of the reasons their daily bowel movements decreased.

Even though there was one significant difference between pre-and post-assessment of the DHQ-3, there was an increase in the intake of essential micronutrients that help slow down PD progression. For example, participant's intake of folate was under the DRI before the virtual program. After the intervention, folate intake increased to 403.61 mcg, which is over the recommendation of adults 51-70 years old. Elevated homocysteine levels are present in PwPD; this might increase dopaminergic cell death. Folate has a role in breaking down homocysteine. This adequate consumption of this vitamin contributes positively to the metabolism of

homocysteine that may potentially lower PD progression (Sherzai, Tagliati, Park, Pezeshkian, & Sherzai, 2016).

Furthermore, participants are under the DRI for calcium, magnesium, and vitamin D. However, intake of these micronutrients increased numerically post-intervention. This increase contributes to improvements in bone health and muscle contractions. Dietary increases in calcium and vitamin D improves bone density by positively impacting bone remodeling and calcium homeostasis (Ciosek, Kot, Kosik-Bogacka, Łanocha-Arendarczyk, & Rotter, 2021).

In PD, oxidative stress and inflammation are increased. With increased age, telomeres shorten, and the body's ability to repair itself decreases. With excessive inflammation, these normal aging processes are increased (Steindler & Reynolds, 2017), contributing to PD progression. After the intervention, participants in this study increased antioxidants like omega-3, vitamin A, vitamin E, and vitamin C. These antioxidants increase help slow down PD progression by contributing to decreased inflammation in the body.

Even though participants still reported constipation, the intake of fiber and water increased numerically post-intervention, which in the long term will aid in decreasing constipation and improve overall hydration. Additionally, consumption of fruits, vegetables, nuts, seeds, and whole grains increased post-intervention, and these foods also contribute to alleviating constipation.

According to the Self-Determination theory, people evolve and grow to master challenges and incorporate new experiences to help them have a better sense of self (Center for self-determination theory, 2021). The increased motivation about nutrition learning demonstrates this better sense of self. Even though pre-and post-evaluation was not significant, there was an increase in motivation to learn about nutrition that is worth exploring in future programs.

Overall, participants' motivation to complete the program without external rewards (intrinsic motivation) was medium. Their interest and enjoyment in the program were high, indicating that the program was interesting and enjoyable to keep their motivation. Additionally, their effort to complete the program was high, indicating the virtual program had elements requiring a high effort or close attention to complete. The participants who completed the IMI reported that this program was valuable, important, and beneficial, indicating this virtual program served their knowledge gaps, desires, and interests.

Participants indicated this virtual program had appropriate length modules, was appealing, had information easy to understand, and provided the participant with new ideas. Most participants reported that this virtual program was worthwhile, helped them learn, and positively impacted their journey with PD. Participants also noted that the objectives per module were achieved, and they increased their knowledge and understanding of nutrition.

This study is not without its limitations. Because this was a pilot study, the sample size was small, and not all participants completed all the surveys. There was no control group. The results need to be interpreted with caution since COVID-19 affected participants' recruitment, dietary patterns, and physical activities. The data presented in this study is self-reported and opens the possibility for desirability bias. Participants of this study are not representative of the whole PD population since people without access to electronic devices and internet services could not enroll in the program. Despite these limitations, this pilot study is an excellent start to understanding what PwPD value in a nutrition education program.

Better marketing strategy and branding of the program could increase the recruitment of participants. Additionally, this program can be part of other self-management PD programs seeking to include nutrition as an added component to provide their participants. A face-to-face

component could help participants clear questions about the topics and feel connected to other participants enhancing participation and completion of this online program.

To our knowledge, this is the first virtual nutrition education program for PwPD and their care-partners reported in the literature. In conclusion, this program was tailored specifically to the knowledge needs of the participants and this population. This virtual program was useful, worthwhile, engaging, and helpful for the participants. Additionally, the program was a resource that helped improve QOL by providing support through nutrition knowledge. This virtual educational resource has the potential to help many PwPD and their care-partners to improve their health through nutrition.

Chapter 4 - Perspectives

How it all started

In 2015, I joined the Meadowlark Hills Parkinson's program in Manhattan, Kansas. I knew little about Parkinson's disease (PD), but I wanted to work with older adults. I first started helping the program with miscellaneous tasks like serving water, delivering papers, making copies. I soon realized that through all these tasks, I began to get to know the program participants. The PD program director was a great mentor. She not only showed me the medical side of PD but the human side. Everyone involve in this PD program are human beings filled with resilience and a desire to fight PD. Later, I created some nutrition educational materials to answer some of their concerns about diet and PD. At this point, I started thinking about making a program or class on nutrition for people with PD and their care partners.

I started by developing some lessons in one of the classes I took as part of my program of study. I researched nutrition education programs for PD, but there was nothing documented in the scientific literature. It was strange that I couldn't find anything when I know there are cooking programs for PD. Maybe they are not interested in reporting their results? Perhaps, during their sessions, they don't gather data that is useful for scientific reporting? Since I love nutrition education, always had, and I didn't find any report on nutrition education for PD, I thought to myself, 'I can make one; I can create a program with data that can be reported.'

PD's nutritional aspect is often overlooked, and many PD foundations are not interested in funding programs that are not geared towards ending the disease or finding a cure. Here I was with an idea to help people, people I knew, people who matter, people who wanted to learn about nutrition; however, at that time, nutrition was not understood as a key priority for most PD foundations. I thought to myself, 'I've done nutrition education with little to no resources before;

I can figure something out.' So, I started to develop my ideas into outlines, steps, and tangible results. I applied for an internal grant, and I got funds to buy food for demonstrations and paper goods. My original idea was to do a face-to-face program, but then COVID hit, and I had to adapt to an online format.

In the midst of COVID-19

In March 2020, COVID-19 came, and most people went into lockdown. Older adults, my main target population, were now prevented from face-to-face interaction. Understandable, they were a high-risk population for the virus, but how would I get my participants? Before COVID, I went to PD groups in Kansas to talk about the program, and I had interested people, but now communication was interrupted. I needed participants to enroll in the program, but communication was complex. I started to reach out to the Parkinson's foundation, the Davis Phinney Foundation, the Michael J. Fox Foundation, but they didn't have an interest in promoting my program for enrollment. I used Facebook PD groups to reach out, but communication was disrupted. It was until I started to contact Davis Phinney ambassadors that I got some responses back. I got invited to their online meeting to talk about nutrition and the program. I got good responses, and people were interested and enrolling in the program.

Focus groups

Twenty-eight people enrolled in the program; I reached out to set up zoom meetings to conduct focus groups and schedule appropriate and convenient times. I had problems with some of the participants' internet connection, others canceled their attendance due to emergency issues, but all of them seemed engaged and interested in helping plan the nutrition program. Most of them agreed that doctors usually don't know about nutrition and PD and don't know where to direct them to learn about it.

During the focus groups, I realized that some of them know their nutrition, and others are starting to discover how nutrition can help PD. It was difficult to not answer their nutrition questions in the focus groups, but I had to remain impartial.

Development of the program

I decided to make the program self-paced because it was difficult to set a time and day for all the participants enrolled. I spent hours deciding layout for written materials, learning how to edit a video with a new software, improving lighting in my recipe videos, and deciding what information was most important, but it was all worth it. I learned skills outside the nutritional sciences that I think help me value and understand the amount of work needed to provide quality health programs.

Lessons learned

- I think I was too ambitious about the number of surveys I asked the participants to fill out. I wanted to have significant data, but I think this might have prevented some participants from completing the program.
- PD is indeed a snowflake disease in the sense that no two people have the same symptoms. Still, according to what participants said about the program, they have similar interests in the nutrition knowledge they want to learn.
- I invested in lighting equipment after seeing my first recipe video, and I don’t regret that investment. The improvement in the last videos compared to the first ones is significant. I think good light helps people to engage with the video.
- Contacting large foundations through their primary email might not be the best strategy to market a PD program. Ambassadors are the ones that are in the front lines fighting PD.

Their insight and advice are what can make a helpful educational program for those they advocate.

How to improve

- I would take more time to market the program and send surveys more than one week before the program starts. I will focus on fewer data outcomes to have higher completion rates.
- I would re-do my videos to have a more uniform layout and lighting. I would like to learn more about video editing to create more engaging videos.
- A participant commented that some concepts were expected to be known. I would spend more time studying the fundamentals of nutrition to make basic concepts clearer that will help them understand which foods are better for PD.
- I would love to do this program face-to-face; I think many of the questions answered in an in-person meeting can be incorporated in the online version.

Chapter 5 - References

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Appendix A - Classification of participants comments by common themes, focus groups.

Question 1 - How many of you have thought about the foods we eat and the effect on Parkinson's? How do you feel about the interaction between the foods you eat and Parkinson's disease? Do you think there is an effect?	
Themes	
Haven't notice anything	"No, I haven't notice anything" "No, I have not either from what we heard from all of the other presenters and research is that there is none yet except to eat a healthy diet and that's the only thing I've heard." "I haven't been worried about my nutrition I'm trying to eat fruits and vegetables, but it gets a little complicated. Healthy for me isn't always the best"
Healthy eating	"I try to eat more vegetables and fruits and nuts since I got diagnosed, I try to watch more what I eat." "I want to stay healthy and I figured good foods are better for you." "I think in general being a good diet is good for everything so it must be good for Parkinson too." "I think we are all encouraged to eat healthy you know so here I am wanting to eat healthy."

	“Some of the medications can cause compulsive Behavior one of them is compulsive eating so that can be an issue with Parkinson's also.” “How bad are certain things, I mean you got to live.” “There are ads that people fall into for example supplements vs no supplements, how much is enough, what's legitimate what's approved what approval matters?” “I know that foods that are not processed are better foods for you. What are good carbs and bad carbs I'm learning the names and kind of the things to look for again.” “How to read the food label, people need to know if you go to the grocery store you read the label and you see these five ingredients in the label then put it down don't buy it so I think like shopping, make some cooking classes.”
Protein and Levodopa	“I'm trying to find out information about the effect of eating protein and how it may affect my meds. So many different answers on the topic and I'm somewhat lost looking for an answer.” “Eating protein when you have your levodopa whether it is before or after how long 30 minutes an hour.” “The biggest interaction I think about is the relationship between protein Sinemet and Carbidopa levodopa and I'm supposed to

	wait a certain amount of time to eat protein before after I take it.” “I've Heard lots of things particularly about protein and the effect it has on levodopa.” “Sometimes protein affects the medicine.” “I don't pay attention to the protein to be honest with you, I eat so much meat that it will be tough to avoid.” “The relationship to protein approaching so 30 to 60 minutes before or after the med you don't eat foods with protein, so you time your drugs around it or around drugs.” “I have known for quite some time that protein would compete with my Sinemet for access.”
Conflicting information	“There is a lot of conflicting information out there, so I think it's helpful to know the effects of various foods, for example, dairy” “Part of the challenge is the conflicted information out there and I think the research you know it's still suggests that there are issues that need to be investigated.” “It's a little bit overwhelming, there's so many experts and so many so many sources but frankly that is the part for me who do you believe.”
Dairy	“There is a lot of conflicting information out there, so I think it's helpful to know the effects of various foods, for example, dairy.”

	“I tried to stay away from the dairy, again not knowing what is right or wrong.” “I think just dairy is considered or is associated with inflammation cow dairy.”
Nausea	“I had terrible nausea when I started taking levodopa and I would have to like carb load basically in order to do not have nausea and stay in bed.” “I've had a little bit of nausea as far as the Carbidopa.”
blood pressure	“If he has too many carbs with eating, anyway, your blood pressure become lower and Carbidopa lowers your blood pressure, a lot of things seem to lower your blood pressure.”
Swallowing difficulties	“I've been looking into diet as well as food that can be processed but still taste good.” “We're looking for high protein good fat foods like avocado.”
Recommended foods	“I do have, about a cup of blueberries every day because that's one of the brain barrier foods that they recommend.”
Question 2 - Where do you get information about nutrition education and Parkinson's?	
Themes	
Programs, foundations, or insurance	“I can reach out to like my blue cross blue shield, community fitness class”

	“The Michael J. Fox and all of the association's you know the Davis Phinney Foundation all of those because I feel they are most reliable.” “Michael J. Fox, Parkinson's Foundation, Davis Phinney. Yeah, the APDA and I think more and more everybody is on the nutrition so.” “ADPA, Parkinson's Foundation, Davis Phinney, Michael J. Fox, movement disorder alliance, those are the main ones out there we get their newsletters.” “Michael J. Fox has good webinars, Davis Phinney has good information; sometimes I go to government websites like PubMed and I we have a local organization regional organization I should say organization called Northwest Parkinson's foundation.” “The book that came out from the Davis Phinney organization all about Parkinson's” “There is a lot of things put on now on zoom and you can actually do research.”
Health professional	“I'll ask my movement specialist about stuff; I'll ask people at the gym too.” “I have brought it up with my doctor but I don't think he was prepared to talk to me about it nutrition and I don't think that the

	med schools do a really good job of educating the docs on that nutrition." "comment the people that are becoming doctors know very little about nutrition and how your body absorbs fats different than carbohydrates they seem to focus on meat bone connected to the bone kind of thing." "Physical therapist and she does a lot with nutrition." "We haven't run into any doctors that have knowledge on food versus disease. My first neurologist was the one that diagnose me and she was a wonderful lady but didn't say anything about exercise or nutrition." "It surprises me that Western doctors are so much in the dark as far as nutrition goes." "The good thing is that most of them understand that they don't have to be an expert on all those subjects but just know where to point you to."
Reliability of resources	"I tried to go to reputable sources like Mayo Clinic, Michael J. Fox or Davis Phinney or the Parkinson's Foundation." "Some of it you have to be careful off where you get your sources off." "I look at the source, where they're getting the information, who is saying it, what are their credentials, what back up do they

	have for." "There are a lot of salesman's out there, this is going to cure your Parkinson along with 27 other diseases." "You have to ask what if their motivation because a lot of these things are infomercials in disguise."
Webinars	"I have seen webinars all nutrition and Parkinson's and for most they don't know enough yet about what's going on in the gut to make any definitive recommendations, except stool softeners and a Mediterranean diet or eat healthy but nothing specific for Parkinson's."
Question 3 - How do you feel about the resources available regarding nutrition education for those affected by Parkinson's?	
Themes	
Conflicted information	"Part of the challenge is the conflicted information out there and I think their research you know it's still suggests that there are issues that need to be investigated." "I'm interested in nutrition but I'm not an expert and not a dietitian." "I'm not a nutritionist that does feel like an area for me that again is critically important but I'm not sure I'm making the best choices are have the best information."
Trackers	"I like to see something like an easy tracker something that you can track what you're eating on a daily basis."

	“I like to see an easy tracker that will help to make sure that I am doing what I'm supposed to be doing.” “I know that with taking meds and all of the things, I tried to time what I eat and when I'm going to take my meds.” “I am old-school I like pieces of paper it will help you I think actually see what you are eating.”
Not enough information	“I don't think there is enough resources about it because what I've heard is that we don't have information and we don't know from some of the doctors that have done the presentations.” “So, for me I would like more if there really is information out there about nutrition.”
Better resources	“It will be nice to have a few handy suggestions without reading a book, guidance that's a good word.” “Everything seems kind of a broad view so maybe having something a little more tailored toward the person.” “I think like basic nutrition is out there whether is related to the Parkinson's or not I think that it's a starting point.” “The fitness guy, he sends this huge newsletter well I just don't read it.” “It'll be nice to have a feedback from others like have you tried these lately kind of like a support group on nutrition. I think a nutrition support group will be fun and not talk about all the

	things that bring us down by let's talk about food and talk about prepare meals." "What I like about this menu is that she breaks down the nutrition components you know the count not just calories, in salt and and sugar and so forth." "I try to balance out all meats and vegetarian meals chicken pork and so forth and try to give a variety and I also insert new recipes that I find and that's been helpful for shopping."
Meal planning	"He has to rely on me to find what resources there are and plan the meals for both." "If someone tells me what to eat, I'll do better if somebody says for breakfast you should have this and lunch and dinner."
Question 4 - What would you benefit the most from a nutrition education program on Parkinson's disease?	
Themes	
Quality of life	"I will benefit from nutrition to improve my quality of life It will be better for me." "I think I benefit the most by having a rational and realistic nutritional advice that might be able to slow the progression of PD and have the best quality of life possible ." "I think one of those things that everybody worries about I don't know as much as about Parkinson's and weight management."

Foods to eat vs foods to avoid	“I will benefit from nutrition to improve my quality of life It will be better for me.” “The types of food you should have versus the types and you shouldn't.” “Come up with like if I eat like this or don't eat this before bedtime or do you eat before bedtime this may or may not help.” “Anything to specifically avoid, that research shows that is disadvantageous for Parkinson's Disease.” “Things that people with Parkinson's shouldn't be eating. I know we usually have gut issues. I'd like to know if there is anything that you absolutely shouldn't do nutritionally if you have Parkinson's.”
Timing of foods and medication	“Timing and medication related to food intake.” “Is that more beneficial than having the main meal at five or six.”
Other chronic conditions	“Interactions with other health conditions for example prediabetes.” “I would like to see if it can reduce my symptoms.” “I have the orthostatic hypotension due to my Parkinson, but I can find a doctor that knows how to control it.” “I don't know but I also have restless leg syndrome due to Parkinson's and if anything, I can eat helps that.”

Constipation/Upset stomach	“with Parkinson's constipation is an issue.” “The constipation I think it's real and what works for one person may not work for somebody else and so it will be nice to hear what some options are.” “PA [physician assistant] gave me two items to look for in probiotics and since I switched to that probiotic things have been much better.” “I think that it would be valuable for every person now that has Parkinson's if they just had a regular gut movement it would be huge.” “My medication makes me constipated so what I have tried to do is eat more food that has fiber in it. This on my own part because I still have to take MiraLAX to help with it. I don’t want to take it so I do try to eat you know healthier and it's still ahh it's it is what it is.” “I love my cheese; however, constipation also runs pretty strong and a lot of Parkinson patients, so I had to back off a little bit on that.” “My Sinemet really upsets my stomach.”
Hydration	“What kind of tea is best for you; which ones are hoaxes and they really don't do anything for you?”

Question 5 - What topics would you consider important to cover in a nutrition education program on Parkinson's disease? What is your preferred learning style?	
Theme	
Tasty food	"I don't like to eat bland food. I like flavor."
Reading Learning style	"I like to read it, I do best with printed material" "I'm old school I liked physical stuff" "I like printed" "If you put it in a large enough size, I can read it." "I like to read so you know reading something sinks in better than just auditory for me."
Visual learning style	"Like to see it and going through steps." "I guess seeing [it], like what we're doing with the video." "so, I like to see it and do it I least like to read it." "I probably do better by hearing and seeing." "People giving me examples is very helpful."
Food book	"Confusing sometimes what is good what is that good for you." "I will like a resource that you can look at food and read about information about the different types of food like meat like the fish something about that."
Webinars	"I get a lot out of webinars."
Participant support	"Talking with other people and learning the tricks of the trade has been very helpful for me."

	“I think what's nice about a focus group like this is that I just wrote down about what the other participant said.”
Confusion on mealtimes	“I always get confused at breakfast time. I don't know what the best thing is to do for Parkinson's breakfast, egg, whites, and eggs you know I always get the breakfast thing I don't know to eat.” “I wander at snack time.”
Inflammation/gut	“Inflammation” “I want to fix everything I can fix without a pill and then go from there you know if I can fix my Gut and not take a stool softener and a probiotic and Miralax that will be fantastic.” “I guess probiotics too will be something I'm interested to and what type of probiotics do you need.” “I really feel strongly there is an inflammation issue in my body and so my goal is to eat food that it's the least inflammatory as possible and so I try to avoid dairy.” “It really feels like the gut-brain connection in Parkinson's is really critical and the second brain the gut.” Parkinson gut Theory really struck home another area that for the landscape seems to be evolving is again back to the gut prebiotics vs. probiotics.”

	“But a lot of the probiotics it seemed to be most effective come from fermented foods but with one of my Parkinson's medicine I take I’m told that you don't you can't have too many fermented foods because it can affect the efficacy of the medication so I feel like it's this vicious circle.”
Other comments	“One of the most complicated things in designing the program has to do with how individualized Parkinson’s is.” “Concerns about organic foods.” “Also shopping during this Covid issue is not easy.” “Cooking school, how to cook in the kitchen to do it ourselves and we can eat the food.” “Before and after working out and just eating healthier.” “Like I said the problem was about concerns when some of our people just really have zero appetite and just stop eating because they're not there to eat and so they get fragile and fall. Then we start to see a really down slide when they don't have enough nutrition.” “I am finding that people don't do that. I wish they were more active more self-advocating.” “The passive people would rather have somebody lay down the game plan for them and say/ We’ll Implement this, we’ll Implement that, we’ll Implement these. They don't want to go

	out and do the research they want somebody hand [it] to them and then say but I don't like things that are green.”

Appendix B - Educational handouts for the program

Appendix C - Demographics and other health-related information questionnaire

Q1 The following questions are about your everyday activities. Please mark only **one** answer for each question.

Q39 Please tell us your current weight in pounds

_____

Q40 Please tell us your current height in feet and inches

_____

Q9 What is your biological gender?

- ○ Male
- ○ Female

Q10 What is your age?

_____

Q11 What is the highest level of education you have completed?

- ○ Some high school
- ○ High school graduate
- ○ Trade/technical/vocational training
- ○ College graduate
- ○ Master's or doctoral degree

Q14 I am

- ○ Married
- ○ Widowed
- ○ Divorced
- ○ Separated
- ○ Never married
- ○ A have a significant other

Q13 I am

- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Pacific Islander
- Hispanic/Latino
- Other

Q15 How long have you been diagnosed with Parkinson's?

_____

Q16 Please indicate your primary living environment

- Home alone
- Home with family
- Assisted living
- Health care

Q4 If you need to explain your answers to the questions above, please use this space if necessary.

_____

_____

_____

_____

_____

Q17 How much time (in minutes) do you spend on planned exercise? Planned exercise will be any time you set aside to purposefully move your body.

_____

Q24 How many days a week do you do planned exercise?

- ○ 1-2 days
- ○ 2-3 days
- ○ 3-4 days
- ○ 4-5 days
- ○ 5-6 days
- ○ 6-7 days

Q18 What physical activities do you do?

_____

Q19 Do you ever drink alcohol?

- ○ Yes
- ○ No

Q20 If yes, please indicate the quantity per week

- ○ Glass of wine (5 oz)_____
- ○ Beer (cans or bottles) _____
- ○ Liquor (shots 1 oz) _____
- ○ Other _____

Q21 Please check one of the following

- ○ Never smoked
- ○ Former smoker
- ○ Smoke some days
- ○ Smoke every day
- ○ Exposed to second hand smoke

Q22 Have you had any recent hospitalization? Please describe

_____

_____

_____

_____

_____

Q23 Do you take medications for other symptoms or ailments besides Parkinson's? If so, please describe

_____

_____

_____

_____

_____

Q25 Do you actively participate in the Parkinson's Program or support group?

- ○ Yes
- ○ Sometimes
- ○ No

Q26 If you participate in the Parkinson's Program or support group which activities do you attend to? If you attend any classes via zoom or online, please indicate those too.

- ○ Chair exercise class
- ○ Yoga class
- ○ Rock steady boxing
- ○ Monthly educational meetings
- ○ Support group for people with Parkinson's
- ○ Support group for care-partners
- ○ Speech classes
- ○ Monthly Luncheons
- ○ Exercise class, standing up
- ○ Other

Q42 If you answered other in the question above, please indicate what activities you are referring to.

_____

Q41
Please tell us what types of medications you take, what are they prescribed for and how much do you take.

Example: Carb/Levo 25/100 for Parkinson's, I take 1 tab

_____

_____

_____

_____

_____

Q27
The bowel is another name for the intestines. Other names for the bowel include guts or innards. Accidental bowel leakage is leaking from the bowel or intestines that can't be controlled. Leakage of gas is also called passing gas, passing wind, or farting.

How often during the past 30 days have you had any amount of accidental bowel leakage that consisted of gas? Would you say . . .

- ○ 2 or more times a day
- ○ once a day
- ○ 2 or more times a week
- ○ once a week
- ○ 1-3 times a month
- ○ never
- ○ Don't know

Q28
Mucus is a thick, jelly-like substance made by the intestines that helps coat and protect the lining of the intestine. Mucus also helps stool pass through the large intestine and rectum more

easily.

How often during the past 30 days have you had any amount of accidental bowel leakage that consisted of mucus?

- 2 OR MORE TIMES A DAY
- ONCE A DAY
- 2 OR MORE TIMES A WEEK
- ONCE A WEEK
- 1-3 TIMES A MONTH
- NEVER
- DON'T KNOW

Q29
Stool is also called a bowel movement, BM, or poop.

How often during the past 30 days have you had any amount of accidental bowel leakage that consisted of liquid stool?

- ○ 2 OR MORE TIMES A DAY
- ○ ONCE A DAY
- ○ 2 OR MORE TIMES A WEEK
- ○ ONCE A WEEK
- ○ 1-3 TIMES A MONTH
- ○ NEVER
- ○ DON'T KNOW

Q30 How often during the past 30 days have you had any amount of accidental bowel leakage that consisted of solid stool?

- ○ 2 OR MORE TIMES A DAY
- ○ ONCE A DAY
- ○ 2 OR MORE TIMES A WEEK
- ○ ONCE A WEEK
- ○ 1-3 TIMES A MONTH
- ○ NEVER
- ○ DON'T KNOW

Q31 How often do you usually have bowel movements? Enter number of times (per week)

_____

Q32 How many times per day or per week do you usually have a bowel movement? Enter number of times (per day)

_____

Q33 Tell me the number that corresponds to your usual or most common stool type

- ○ Type 1
- ○ Type 2
- ○ Type 3
- ○ Type 4
- ○ Type 5
- ○ Type 6
- ○ Type 7

Q34 During the past 12 months, how often have you had an urgent need to empty your bowels that makes you rush to the toilet? Would you say...

- ○ always
- ○ most of the time
- ○ sometimes
- ○ rarely
- ○ never
- ○ don't know

Q35 During the past 12 months, how often have you been constipated?

- ○ always
- ○ most of the time
- ○ sometimes
- ○ rarely
- ○ Never
- ○ don't know

Q36 During the past 12 months, how often have you had diarrhea?

- ○ always
- ○ most of the time
- ○ sometimes
- ○ rarely
- ○ Never
- ○ don't know

Q37 In the past 30 days, did you take any laxatives or stool softeners, such as Ex-Lax, Metamucil or Fiber-all, to help move your bowels?

- ○ Yes
- ○ No
- ○ Don't know

Q38 How many times have you taken laxatives or stool softeners in the past 30 days? Would you say...

- most days
- 1-3 times a week
- 2-3 times a month
- once a month
- don't know
- not applicable

Q43 Please tell us your name, this is for record keeping only. This information will not be published or shared with the media or other companies.

_____

Q44 Which state are you located in?

_____

Q45 Please tell us your email so we can contact you.

_____

Q46 If you attend to any Parkinson's group or you receive a periodically newsletter, please indicate from which program.

_____

Q47 You are a

- ○ Person with Parkinson's
- ○ Care-partner
- ○ Health professional auditing this course

Q49 Please write your name and last name. This information will not be shared or included in data analysis. The purpose of this question is to keep track of who has answered the survey and if you want your results at the end of the study, it will help us to pull the correct information.

_____

End of Block: Default Question Block

Appendix D - Diet History Questionnaire (DHQ3) from the National Cancer Institute

Appendix E - Mini Nutritional Assessment (MNA)

Q1 Please fill out these questions to the best of your knowledge

Q2 Are you

- ○ Female
- ○ Male

Q3 Please tell us your age

_____

Q4 Please tell us how much you weight is pounds

_____

Q5 Please tell us what is your height in feet and inches

_____

Q11
Measure the circumference of your LEFT calf by following the instructions below:
1. Loop a tape measure all the way around your calf to measure its size.
2. In the box below, please tell us the measurement you took of you left calf.

_____

Q6 Has your food intake declined over the past 3 months?

- ○ severe decrease in food intak
- ○ moderate decrease in food intake
- ○ no decrease in food intake

Q7 How much weight have you lost in the past 3 months?

- ○ weight loss greater than 7 pounds
- ○ do not know the amount of weight lost
- ○ weight loss between 2 and 7 pounds
- ○ no weight loss or weight loss less than 2 pounds

Q8
How would you describe your current mobility?

- ○ unable to get out of a bed, a chair, or a wheelchair without the assistance of another person
- ○ able to get out of bed or a chair, but unable to go out of my home
- ○ able to leave my home

Q9 Have you been stressed or severely ill in the past 3 months?

- ○ Yes
- ○ No

Q10
Are you currently experiencing dementia and/or prolonged severe sadness?

- ○ yes, severe dementia and/or prolonged severe sadness
- ○ yes, mild dementia, but no prolonged severe sadness
- ○ no psychological problems

Q13 Please write your name and last name. This information will not be shared or included in data analysis. The purpose of this question is to keep track of who has answered the survey and if you want your results at the end of the study, it will help us to pull the correct information.

_____

End of Block: Default Question Block

Appendix F - Parkinson's disease quality of life measured (PDQ-39)

Q1
Please complete the following questions. Please tick one box for each question.

Due to having Parkinson's disease,how often during the **LAST MONTH** have you....

Q2 Had difficulty doing the leisure activities which you would like to do?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q3 Had difficulty looking after your home, e.g. DIY, housework, cooking?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q4 Had difficulty carrying bags of shopping?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q6 Had problems walking half a mile?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q7 Had problems walking 100yards?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q8 Had problems getting around the house as easily as you would like?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q9 Had difficulty getting around in public?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q10 Needed someone else to accompany you when you went out?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q11 Felt frightened or worried about falling over in public?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q12 Been confined to the house more than you would like?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q13 Had difficulty washing yourself?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q14 Had difficulty dressing yourself?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q15 Had problems doing up your shoe laces?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q16 Had problems writing clearly?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q17 Had difficulty cutting up your food?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q18 Had difficulty holding a drink without spilling it?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q19 Felt depressed?

- Never
- Occasionally
- Sometimes
- Often
- Always or cannot do at all

Q20 Felt isolated and lonely?

- Never
- Occasionally
- Sometimes
- Often
- Always or cannot do at all

Q21 Felt weepy or tearful?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q22 Felt angry or bitter?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q23 Felt anxious?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q24 Felt worried about your future?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q25 Felt you had to conceal your Parkinson's from people?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q26 Avoided situations which involve eating or drinking in public?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q27 Felt embarrassed in public due to having Parkinson's disease?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q28 Felt worried by other people's reaction to you?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q29 Had problems with your close personal relationships?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q30 Lacked support in the ways you need from your spouse or partner?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all
- ○ I do not have a spouse or partner

Q31 Lacked support in the ways you need from your family or close friends?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q32 Unexpectedly fallen asleep during the day?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q33 Had problems with your concentration, e.g. when reading or watching TV?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q34 Felt your memory was bad?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q35 Had distressing dreams or hallucinations?

- Never
- Occasionally
- Sometimes
- Often
- Always or cannot do at all

Q36 Had difficulty with your speech?

- Never
- Occasionally
- Sometimes
- Often
- Always or cannot do at all

Q37 Felt unable to communicate with people properly?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q38 Felt ignored by people?

- ○ Never
- ○ Occasionally
- ○ Sometimes
- ○ Often
- ○ Always or cannot do at all

Q39 Had painful muscle cramps or spasms?

- Never
- Occasionally
- Sometimes
- Often
- Always or cannot do at all

Q40 Had aches and pains in your joints or body?

- Never
- Occasionally
- Sometimes
- Often
- Always or cannot do at all

Q41 Felt unpleasantly hot or cold?

- Never
- Occasionally
- Sometimes
- Often
- Always or cannot do at all

Q43 Please write your name and last name. This information will not be shared or included in data analysis. The purpose of this question is to keep track of who has answered the survey and if you want your results at the end of the study, it will help us to pull the correct information.

_____

End of Block: Default Question Block

Appendix G - Unified Parkinson's Disease Rating Scale (UPDRS)

Q1 Please fill out this survey as truthfully as you can

Q2 Part I. Mentation, Behavior and Mood

Q3 How is your intellectual impairment

- ○ None
- ○ Moderate memory loss, with disorientation and moderate difficulty handling complex problems.
- ○ Mild but definite impairment of function at home with need of occasional prompting.
- ○ Severe memory loss with disorientation for time and often to place. Severe impairment in handling problems.
- ○ Severe memory loss with orientation preserved to person only. Unable to make judgements or solve problems. Requires much help with personal care. Cannot be left alone at all.

Q4 Thought Disorder (Due to dementia or drug intoxication)

- None
- Vivid dreaming.
- “Benign” hallucinations with insight retained.
- Occasional to frequent hallucinations or delusions; without insight; could interfere with daily activities.
- Persistent hallucinations, delusions, or florrid psychosis. Not able to care for self.

Q5 Depression

- None
- Periods of sadness or guilt greater than normal, never sustained for days or weeks.
- Sustained depression (1 week or more).
- Sustained depression with vegetative symptoms (insomnia, anorexia, weight loss, loss of interest).
- Sustained depression with vegetative symptoms and suicidal thoughts or intent.

Q6 Motivation/Initiative

- ○ Normal.
- ○ Less assertive than usual; more passive.
- ○ Loss of initiative or disinterest in elective (nonroutine) activities.
- ○ Loss of initiative or disinterest in day to day (routine) activities.
- ○ Withdrawn, complete loss of motivation.

Q7 Part II. ACTIVITIES OF DAILY LIVING

Q8 Speech on your "on" periods

- ○ Normal
- ○ Mildly affected. No difficulty being understood.
- ○ Moderately affected. Sometimes asked to repeat statements.
- ○ Severely affected. Frequently asked to repeat statements.
- ○ Unintelligible most of the time.

Q21 Speech on your "OFF" periods

- ○ Normal
- ○ Mildly affected. No difficulty being understood.
- ○ Moderately affected. Sometimes asked to repeat statements.
- ○ Severely affected. Frequently asked to repeat statements.
- ○ Unintelligible most of the time.

Q9 Salivation on your "on" periods

- ○ Normal
- ○ Slight but definite excess of saliva in mouth; may have nighttime drooling.
- ○ Moderately excessive saliva; may have minimal drooling.
- ○ Marked excess of saliva with some drooling.
- ○ Marked drooling, requires constant tissue or handkerchief.

Q34 Salivation on your "OFF" periods

- ○ Normal
- ○ Slight but definite excess of saliva in mouth; may have nighttime drooling.
- ○ Moderately excessive saliva; may have minimal drooling.
- ○ Marked excess of saliva with some drooling.
- ○ Marked drooling, requires constant tissue or handkerchief.

Q10
Swallowing on your "on" periods

- ○ Normal
- ○ Rare choking.
- ○ Occasional choking.
- ○ Requires soft food
- ○ Requires Naso-gastric tube or gastrotomy feeding.

Q22
Swallowing on your "OFF" periods

- ○ Normal
- ○ Rare choking.
- ○ Occasional choking.
- ○ Requires soft food
- ○ Requires Naso-gastric tube or gastrotomy feeding.

Q11 Handwriting on your "on" periods

- ○ Normal
- ○ Slightly slow or small
- ○ Moderately slow or small; all words are legible.
- ○ Severely affected; not all words are legible.
- ○ The majority of words are not legible.

Q23 Handwriting on your "OFF" periods

- ○ Normal
- ○ Slightly slow or small
- ○ Moderately slow or small; all words are legible.
- ○ Severely affected; not all words are legible.
- ○ The majority of words are not legible.

Q13 Cutting food and handling utensils on your "on" periods

- ○ Normal
- ○ Somewhat slow and clumsy, but no help needed.
- ○ Can cut most foods, although clumsy and slow; some help needed.
- ○ Food must be cut by someone, but can still feed slowly
- ○ Needs to be fed.

Q24 Cutting food and handling utensils on your "OFF" periods

- ○ Normal
- ○ Somewhat slow and clumsy, but no help needed.
- ○ Can cut most foods, although clumsy and slow; some help needed.
- ○ Food must be cut by someone, but can still feed slowly
- ○ Needs to be fed.

Q12 Dressing on your "on" periods

- ○ Normal
- ○ Somewhat slow, but no help needed
- ○ Occasional assistance with buttoning, getting arms in sleeves.
- ○ Considerable help required, but can do some things alone.
- ○ Helpless

Q25 Dressing on your "OFF" periods

- ○ Normal
- ○ Somewhat slow, but no help needed
- ○ Occasional assistance with buttoning, getting arms in sleeves.
- ○ Considerable help required, but can do some things alone.
- ○ Helpless

Q14 Hygiene on your "on" periods

- ○ Normal.
- ○ Somewhat slow, but no help needed.
- ○ Needs help to shower or bathe; or very slow in hygienic care.
- ○ Requires assistance for washing, brushing teeth, combing hair, going to bathroom.
- ○ Foley catheter or other mechanical aids

Q26 Hygiene on your "OFF" periods

- ○ Normal.
- ○ Somewhat slow, but no help needed.
- ○ Needs help to shower or bathe; or very slow in hygienic care.
- ○ Requires assistance for washing, brushing teeth, combing hair, going to bathroom.
- ○ Foley catheter or other mechanical aids

Q15 Turning in bed and adjusting bed clothes on your "on" periods

- ○ Normal
- ○ Somewhat slow and clumsy, but no help needed
- ○ Can turn alone or adjust sheets, but with great difficulty
- ○ Can initiate, but not turn or adjust sheets alone.
- ○ Helpless

Q27 Turning in bed and adjusting bed clothes on your "OFF" periods

- ○ Normal
- ○ Somewhat slow and clumsy, but no help needed
- ○ Can turn alone or adjust sheets, but with great difficulty
- ○ Can initiate, but not turn or adjust sheets alone.
- ○ Helpless

Q16 Falling (unrelated to freezing) on your "on" periods

- ○ None
- ○ Rare falling.
- ○ Occasionally falls, less than once per day.
- ○ Falls an average of once daily.
- ○ Falls more than once daily.

Q28 Falling (unrelated to freezing) on your "OFF" periods

- None
- Rare falling.
- Occasionally falls, less than once per day.
- Falls an average of once daily.
- Falls more than once daily.

Q17 Freezing when walking on your "on" periods

- None
- Rare freezing when walking; may have starthesitation.
- Occasional freezing when walking.
- Frequent freezing. Occasionally falls from freezing.
- Frequent falls from freezing.

Q29 Freezing when walking on your "OFF" periods

- ○ None
- ○ Rare freezing when walking; may have starthesitation.
- ○ Occasional freezing when walking.
- ○ Frequent freezing. Occasionally falls from freezing.
- ○ Frequent falls from freezing.

Q18 Walking on your "on" periods

- ○ Normal
- ○ Mild difficulty. May not swing arms or may tend to drag leg
- ○ Moderate difficulty, but requires little or no assistance.
- ○ Severe disturbance of walking, requiring assistance.
- ○ Cannot walk at all, even with assistance

Q30 Walking on your "OFF" periods

- ○ Normal
- ○ Mild difficulty. May not swing arms or may tend to drag leg
- ○ Moderate difficulty, but requires little or no assistance.
- ○ Severe disturbance of walking, requiring assistance.
- ○ Cannot walk at all, even with assistance

Q19 Tremor (Symptomatic complaint of tremor in any part of body.) on your "on" periods

- ○ Absent.
- ○ Slight and infrequently present.
- ○ Moderate; bothersome to patient.
- ○ Severe; interferes with many activities.
- ○ Marked; interferes with most activities.

Q31 Tremor (Symptomatic complaint of tremor in any part of body.) on your "OFF" periods

- ○ Absent.
- ○ Slight and infrequently present.
- ○ Moderate; bothersome to patient.
- ○ Severe; interferes with many activities.
- ○ Marked; interferes with most activities.

Q20 Sensory complaints related to parkinsonism on your "on" periods

- ○ None
- ○ Occasionally has numbness, tingling, or mild aching.
- ○ Frequently has numbness, tingling, or aching; not distressing.
- ○ Frequent painful sensations.
- ○ Excruciating pain.

Q32 Sensory complaints related to parkinsonism on your "OFF" periods

- ○ None
- ○ Occasionally has numbness, tingling, or mild aching.
- ○ Frequently has numbness, tingling, or aching; not distressing.
- ○ Frequent painful sensations.
- ○ Excruciating pain.

Q35 IV COMPLICATIONS OF THERAPY (In the past week)

Q36 DYSKINESIAS Duration: What proportion of the waking day are dyskinesias present? (Historical information.)

- ○ None
- ○ 1-25% of day
- ○ 26-50% of day.
- ○ 51-75% of day.
- ○ 76-100% of day.

Q37 DYSKINESIAS Disability: How disabling are the dyskinesias? (Historical information)

- ○ Not disabling.
- ○ Mildly disabling.
- ○ Moderately disabling.
- ○ Severely disabling.
- ○ Completely disabled.

Q38 Painful Dyskinesias: How painful are the dyskinesias?

- ○ No painful dyskinesias.
- ○ Slight.
- ○ Moderate.
- ○ Severe
- ○ Marked

Q39 Presence of Early Morning Dystonia (Historical information.)

- ○ No
- ○ Yes

Q41 B. CLINICAL FLUCTUATIONS

Q40 Are “off” periods predictable?

- ○ No
- ○ Yes

Q42 Are “off” periods unpredictable?

- ○ No
- ○ Yes

Q43 Do “off” periods come on suddenly, within a few seconds?

- ○ No
- ○ Yes

Q44 What proportion of the waking day is the patient “off” on average?

- ○ None
- ○ 1-25% of day.
- ○ 26-50% of day.
- ○ 51-75% of day.
- ○ 76-100% of day.

Q45 Do you have anorexia, nausea, or vomiting?

- ○ No
- ○ Yes

Q46 Any sleep disturbances, such as insomnia or hypersomnolence?

- ○ No
- ○ Yes

Q47 Do you have symptomatic orthostasis?

- ○ No
- ○ Yes

Q49 Please write your name and last name. This information will not be shared or included in data analysis. The purpose of this question is to keep track of who has answered the survey and if you want your results at the end of the study, it will help us to pull the correct information.

_____

End of Block: Default Question Block

Appendix H - CHAMPS activities questionnaire for older adults

Q127
This questionnaire is about activities that you may have done in the past 4 weeks.

The questions on the following pages are similar to the example shown below.

INSTRUCTIONS:If you DID the activity in the past 4 weeks:

Step #1Check the YES box.

Step #2Think about how many TIMES a week you usually did it, and write your response in the space provided.

Step #3Circle how many TOTAL HOURS in a typical week you did the activity.

Here is an example of how Mrs. Jones would answer question #1:Mrs. Jones usually visits her friends Maria and Olga twice a week. She usually spends one hour on Monday with Maria and two hours on Wednesday with Olga. Therefore, the total hours a week that she visits with friends is 3 hours a week.

If you DID NOT do the activity: Check the NO box and you will be redirected to the next question

Q128 1. In a typical week during the past 4 weeks, did you visit with friends or family (other than those you live with)?

- ○ Yes
- ○ No

Skip To: Q131 If 1. In a typical week during the past 4 weeks, did you visit with friends or family (other than th... = No

Q129 1. Visit with friends or family (other than those you live with)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q130 1. How many TOTAL hours a week did you visit with friends or family (other than those you live with)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q131 2. In a typical week during the past 4 weeks, did you go to the senior center?

- ○ Yes
- ○ No

Q132 2. In a typical week during the past 4 weeks, did you go to the senior center? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q133 2. How many TOTAL hours a week did you did you go to the senior center??

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q134 3. In a typical week during the past 4 weeks, do volunteer work?

- ○ Yes
- ○ No

Q135 3. In a typical week during the past 4 weeks, do volunteer work? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q136 3. How many TOTAL hours a week did you do volunteer work???

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q137 4. In a typical week during the past 4 weeks, did you attend church or take part in church activities?

- ○ Yes
- ○ No

Q138 4. In a typical week during the past 4 weeks, attend church or take part in church activities? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q139 3. How many TOTAL hours a week did you attend church or take part in church activities????

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q140 5. In a typical week during the past 4 weeks, did you attend other club or group meetings?

- ○ Yes
- ○ No

Q141 5. In a typical week during the past 4 weeks, did you attend other club or group meetings? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q142 4. How many TOTAL hours a week did you attend other club or group meetings?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q143 5. In a typical week during the past 4 weeks, did you use a computer?

- ○ Yes
- ○ No

Q144 5. In a typical week during the past 4 weeks, did you use a computer? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q145 5. How many TOTAL hours a week did you use a computer?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q146 6. In a typical week during the past 4 weeks, did you use a computer?

- ○ Yes
- ○ No

Q147 6. In a typical week during the past 4 weeks, did you use a computer? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q148 6. How many TOTAL hours a week did you use a computer?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q149 7. In a typical week during the past 4 weeks, did you dance (such as square, folk, line, ballroom) (do not count aerobic dance here)?

- ○ Yes
- ○ No

Q150 7. In a typical week during the past 4 weeks, did you dance (such as square, folk, line, ballroom) (do not count aerobic dance here)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q151 6. How many TOTAL hours a week did you dance (such as square, folk, line, ballroom) (do not count aerobic dance here)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q152 8. In a typical week during the past 4 weeks, did you do woodworking, needlework, drawing, or other arts or crafts?

- ○ Yes
- ○ No

Q153 8. In a typical week during the past 4 weeks, did you do woodworking, needlework, drawing, or other arts or crafts? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q154 8. How many TOTAL hours a week did you do woodworking, needlework, drawing, or other arts or crafts?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q155 9. In a typical week during the past 4 weeks, did you Play golf, carrying or pulling your equipment (count walking time only)?

- ○ Yes
- ○ No

Q156 9. In a typical week during the past 4 weeks, did you Play golf, carrying or pulling your equipment (count walking time only)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q157 9. How many TOTAL hours a week did you Play golf, carrying or pulling your equipment (count walking time only)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q158 10. In a typical week during the past 4 weeks, did you Play golf, riding a cart (count walking time only)?

- ○ Yes
- ○ No

Q159 10. In a typical week during the past 4 weeks, did you Play golf, riding a cart (count walking time only)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q160 10. How many TOTAL hours a week did you Play golf, riding a cart (count walking time only)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q161 11. In a typical week during the past 4 weeks, did you attend a concert, movie, lecture, or sport event?

- ○ Yes
- ○ No

Q162 11. In a typical week during the past 4 weeks, did you attend a concert, movie, lecture, or sport event? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q163 11. In a typical week during the past 4 weeks, did you attend a concert, movie, lecture, or sport event?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q164 12. In a typical week during the past 4 weeks, did you Play cards, bingo, or board games with other people?

- ○ Yes
- ○ No

Q165 12. In a typical week during the past 4 weeks, did you Play cards, bingo, or board games with other people? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q166 12. How many TOTAL hours a week did you play cards, bingo, or board games with other people?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q167 13. In a typical week during the past 4 weeks, did you Shoot pool or billiards?

- ○ Yes
- ○ No

Q168 13. In a typical week during the past 4 weeks, did you Shoot pool or billiards? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q169 13. How many TOTAL hours a week did you Shoot pool or billiards?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q170 14. In a typical week during the past 4 weeks, did you Play singles tennis (do not count doubles)?

- ○ Yes
- ○ No

Q171 14. In a typical week during the past 4 weeks, did you Play singles tennis (do not count doubles)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q172 14. How many TOTAL hours a week did you Play singles tennis (do not count doubles)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q173 15. In a typical week during the past 4 weeks, did you Play doubles tennis (do not count singles)?

- ○ Yes
- ○ No

Q174 15. In a typical week during the past 4 weeks, did you Play doubles tennis (do not count singles)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q175 15. How many TOTAL hours a week did you Play doubles tennis (do not count singles)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q176 16. In a typical week during the past 4 weeks, did you Skate (ice, roller, in-line)?

- ○ Yes
- ○ No

Q177 16. In a typical week during the past 4 weeks, did you Skate (ice, roller, in-line)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q178 16. How many TOTAL hours a week did you Skate (ice, roller, in-line)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q179 17. In a typical week during the past 4 weeks, did you Play a musical instrument?

- ○ Yes
- ○ No

Q180 17. In a typical week during the past 4 weeks, did you Play a musical instrument? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q181 17. How many TOTAL hours a week did you Play a musical instrument?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q182 18. In a typical week during the past 4 weeks, did you read?

- ○ Yes
- ○ No

Q183 18. In a typical week during the past 4 weeks, did you read? If yes, how many TIMES a week?

- 1
- 2
- 3
- 4
- 5
- 6
- 7

Q184 18. How many TOTAL hours a week did you read?

- Less than 1 hour
- 1-2½ hours
- 3-4½ hours
- 5-6½ hours
- 7-8½ hours
- 9 or more hours

Q185 19. In a typical week during the past 4 weeks, did you Do heavy work around the house (such as washing windows, cleaning gutters)?

- ○ Yes
- ○ No

Q186 19. In a typical week during the past 4 weeks, did you Do heavy work around the house (such as washing windows, cleaning gutters)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q187 19. How many TOTAL hours a week did you Do heavy work around the house (such as washing windows, cleaning gutters)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q188 20. In a typical week during the past 4 weeks, did you Do light work around the house (such as sweeping or vacuuming)?

- ○ Yes
- ○ No

Q189 20. In a typical week during the past 4 weeks, did you Do light work around the house (such as sweeping or vacuuming)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q190 20. How many TOTAL hours a week did you Do light work around the house (such as sweeping or vacuuming)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q191 21. In a typical week during the past 4 weeks, did you Do heavy gardening (such as spading, raking)?

- ○ Yes
- ○ No

Q192 21. In a typical week during the past 4 weeks, did you Do heavy gardening (such as spading, raking)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q193 21. How many TOTAL hours a week did you Do heavy gardening (such as spading, raking)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q194 22. In a typical week during the past 4 weeks, did you Do light gardening (such as watering plants)?

- ○ Yes
- ○ No

Q195 22. In a typical week during the past 4 weeks, did you Do light gardening (such as watering plants)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q196 22. How many TOTAL hours a week did you Do light gardening (such as watering plants)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q197 23. In a typical week during the past 4 weeks, did you Work on your car, truck, lawn mower, or other machinery?

- ○ Yes
- ○ No

Q198 23. In a typical week during the past 4 weeks, did you Work on your car, truck, lawn mower, or other machinery? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q199 22. How many TOTAL hours a week did you Do light gardening (such as watering plants)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q200 *Please note: For the following questions about running and walking, include use of a treadmill

---

Q201 23. In a typical week during the past 4 weeks, did you Work on your car, truck, lawn mower, or other machinery?

- ○ Yes
- ○ No

Q202 23. In a typical week during the past 4 weeks, did you Work on your car, truck, lawn mower, or other machinery? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q203 23. How many TOTAL hours a week did you Work on your car, truck, lawn mower, or other machinery?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q205 24. In a typical week during the past 4 weeks, did you Jog or run?

- ○ Yes
- ○ No

Q206 24. In a typical week during the past 4 weeks, did you Jog or run? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q207 24. How many TOTAL hours a week did you Jog or run?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q208 25. In a typical week during the past 4 weeks, did you Walk uphill or hike uphill (count only uphill part)?

- ○ Yes
- ○ No

Q209 25. In a typical week during the past 4 weeks, did you Walk uphill or hike uphill (count only uphill part)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q210 25. How many TOTAL hours a week did you Walk uphill or hike uphill (count only uphill part)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q211 26. In a typical week during the past 4 weeks, did you Walk fast or briskly for exercise (do not count walking leisurely or uphill)?

- ○ Yes
- ○ No

Q212 26. In a typical week during the past 4 weeks, did you Walk fast or briskly for exercise (do not count walking leisurely or uphill)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q213 26. How many TOTAL hours a week did you Walk fast or briskly for exercise (do not count walking leisurely or uphill)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q214 27. In a typical week during the past 4 weeks, did you Walk to do errands(such as to/from a store or to take children to school (count walk time only)?

- ○ Yes
- ○ No

Q215 27. In a typical week during the past 4 weeks, did you Walk to do errands(such as to/from a store or to take children to school (count walk time only)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q216 27. How many TOTAL hours a week did you Walk to do errands(such as to/from a store or to take children to school (count walk time only)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q217 28. In a typical week during the past 4 weeks, did you Walk leisurely for exercise or pleasure?

- ○ Yes
- ○ No

Q218 28. In a typical week during the past 4 weeks, did you Walk leisurely for exercise or pleasure? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q219 28. How many TOTAL hours a week did you Walk leisurely for exercise or pleasure?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q220 29. In a typical week during the past 4 weeks, did you Ride a bicycle or stationary cycle?

- ○ Yes
- ○ No

Q221 29. In a typical week during the past 4 weeks, did you Ride a bicycle or stationary cycle? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q222 29. How many TOTAL hours a week did you Ride a bicycle or stationary cycle?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q223 30. In a typical week during the past 4 weeks, did you Do other aerobic machines such as rowing, or step machines (do not count treadmill or stationary cycle)?

- ○ Yes
- ○ No

Q224 30. In a typical week during the past 4 weeks, did you Do other aerobic machines such as rowing, or step machines (do not count treadmill or stationary cycle)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q225 30. How many TOTAL hours a week did you Do other aerobic machines such as rowing, or step machines (do not count treadmill or stationary cycle)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q226 31. In a typical week during the past 4 weeks, did you Do water exercises (do not count other swimming)?

- ○ Yes
- ○ No

Q227 31. In a typical week during the past 4 weeks, did you Do water exercises (do not count other swimming)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q228 31. How many TOTAL hours a week did you Do water exercises (do not count other swimming)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q229 32. In a typical week during the past 4 weeks, did you Swim moderately or fast?

- ○ Yes
- ○ No

Q230 32. In a typical week during the past 4 weeks, did you Swim moderately or fast? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q231 32. How many TOTAL hours a week did you Swim moderately or fast?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q232 33. In a typical week during the past 4 weeks, did you Swim gently?

- ○ Yes
- ○ No

Q233 33. In a typical week during the past 4 weeks, did you Swim gently? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q234 33. How many TOTAL hours a week did you Swim gently?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q235 34. In a typical week during the past 4 weeks, did you Do stretching or flexibility exercises (do not count yoga or Tai-chi)?

- ○ Yes
- ○ No

Q236 34. In a typical week during the past 4 weeks, did you Do stretching or flexibility exercises (do not count yoga or Tai-chi)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q237 34. How many TOTAL hours a week did you Do stretching or flexibility exercises (do not count yoga or Tai-chi)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q238 35. In a typical week during the past 4 weeks, did you Do yoga or Tai-chi?

- ○ Yes
- ○ No

Q239 35. In a typical week during the past 4 weeks, did you Do yoga or Tai-chi? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q240 35. How many TOTAL hours a week did you Do yoga or Tai-chi?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q241 36. In a typical week during the past 4 weeks, did you Do aerobics or aerobic dancing?

- ○ Yes
- ○ No

Q242 36. In a typical week during the past 4 weeks, did you Do aerobics or aerobic dancing? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q243 36. How many TOTAL hours a week did you Do aerobics or aerobic dancing?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q244 37. In a typical week during the past 4 weeks, did you Do moderate to heavy strength training (such as hand-held weights of more than 5 lbs., weight machines, or push-ups)?

- ○ Yes
- ○ No

Q245 37. In a typical week during the past 4 weeks, did you Do moderate to heavy strength training (such as hand-held weights of more than 5 lbs., weight machines, or push-ups)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q246 37. How many TOTAL hours a week did you Do moderate to heavy strength training (such as hand-held weights of more than 5 lbs., weight machines, or push-ups)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q247 38. In a typical week during the past 4 weeks, did you Do light strength training (such as hand-held weights of 5 lbs. or lessor elastic bands)?

- ○ Yes
- ○ No

Q248 38. In a typical week during the past 4 weeks, did you Do light strength training (such as hand-held weights of 5 lbs. or lessor elastic bands)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q249 38. How many TOTAL hours a week did you Do light strength training (such as hand-held weights of 5 lbs. or lessor elastic bands)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q250 39. In a typical week during the past 4 weeks, did you Do general conditioning exercises, such as light calisthenics or chair exercises (do not count strength training)?

- ○ Yes
- ○ No

Q251 39. In a typical week during the past 4 weeks, did you Do general conditioning exercises, such as light calisthenics or chair exercises (do not count strength training)? If yes, how many TIMES a week?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q252 39. How many TOTAL hours a week did you Do general conditioning exercises, such as light calisthenics or chair exercises (do not count strength training)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q253 40. In a typical week during the past 4 weeks, did you Play basketball, soccer, or racquetball (do not count time on sidelines)?

- ○ Yes
- ○ No

Q254 40. In a typical week during the past 4 weeks, did you Play basketball, soccer, or racquetball (do not count time on sidelines)? If yes, how many TIMES a week

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q255 40. How many TOTAL hours a week did you Play basketball, soccer, or racquetball (do not count time on sidelines)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q256 41. In a typical week during the past 4 weeks, did you Do other types of physical activity not previously mentioned (please specify)?

- ○ Yes
- ○ No

Q257 41. In a typical week during the past 4 weeks, did you Do other types of physical activity not previously mentioned (please specify)? If yes, how many TIMES a week

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7

Q258 41. How many TOTAL hours a week did you Do other types of physical activity not previously mentioned (please specify)?

- ○ Less than 1 hour
- ○ 1-2½ hours
- ○ 3-4½ hours
- ○ 5-6½ hours
- ○ 7-8½ hours
- ○ 9 or more hours

Q132 Please write your name and last name. This information will not be shared or included in data analysis. The purpose of this question is to keep track of who has answered the survey and if you want your results at the end of the study, it will help us to pull the correct information.

_____

End of Block: Block 1

Appendix I - Motivation inventory

Q1 The following question relates to the reasons why you would either start eating a healthier diet or continue to do so. Different people have different reasons for doing that, and we want to know how true each of the followingreasons is for you. All 15 response are to the same question.

Please indicate the extent to which each reason is true for you, using the following 7-point scale:
1 = not at all true
2
3
4 = somewhat true
5
6
7 = very true

Q2 The reason I would eat a healthy diet for Parkinson's is because I feel that I want to take responsibility for my own health.

- ○ 1= Not true
- ○ 2
- ○ 3
- ○ 4= Somewhat true
- ○ 5
- ○ 6
- ○ 7 = Very true

Q3 The reason I would eat a healthy diet for Parkinson's is because I would feel guilty or ashamed of myself if I did not eat a healthy diet for Parkinson's.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q4 The reason I would eat a healthy diet for Parkinson's is because personally believe it is the best thing for my health.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q5 The reason I would eat a healthy diet for Parkinson's is because others would be upset with me if I did not.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q8 The reason I would eat a healthy diet for Parkinson's is... I really don't think about it.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q9 The reason I would eat a healthy diet for Parkinson's is because I have carefully thought about it and believe it is very important for many aspects of my life.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q10 The reason I would eat a healthy diet for Parkinson's is because I would feel bad about myself if I did not eat a healthy diet for Parkinson's.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q11 The reason I would eat a healthy diet for Parkinson's is because it is an important choice I really want to make.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q12 The reason I would eat a healthy diet for Parkinson's is because I feel pressure from others to do so.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q13 The reason I would eat a healthy diet for Parkinson's is because it is easier to do what I am told than think about it.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q14 The reason I would eat a healthy diet for Parkinson's is because it is consistent with my life goals.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q15 The reason I would eat a healthy diet for Parkinson's is because I want others to approve of me.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q16 The reason I would eat a healthy diet for Parkinson's is because it is very important for being as healthy as possible.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q17 The reason I would eat a healthy diet for Parkinson's is because I want others to see I can do it.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q18 The reason I would eat a healthy diet for Parkinson's is because... I don't really know why.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q20 I feel confident in my ability to maintain a healthy diet for Parkinson's.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q21 I now feel capable of maintaining a healthy diet for Parkinson's.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q22 I am able to maintain a healthy diet for Parkinson's permanently.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q23 I am able to meet the challenge of maintaining a healthy diet for Parkinson's.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q24 I feel that my health-care practitioners have provided me with choices and options about changing my
diet (including not changing).

- ○ 1= Not true
- ○ 2
- ○ 3
- ○ 4= Somewhat true
- ○ 5
- ○ 6
- ○ 7 = Very true

Q25 I feel my health-care providers understand how I see things with respect to my diet.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q26 My health-care providers convey confidence in my ability to make changes regarding my diet.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q27 My health care practitioners listen to how I would like to do things regarding my diet.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q28 My health-care practitioners encourage me to ask questions about my diet.

- 1= Not true
- 2
- 3
- 4= Somewhat true
- 5
- 6
- 7 = Very true

Q29 My health-care practitioners try to understand how I see my diet before suggesting any changes.

- ○ 1= Not true
- ○ 2
- ○ 3
- ○ 4= Somewhat true
- ○ 5
- ○ 6
- ○ 7 = Very true

Q31 Please write your name and last name. This information will not be shared or included in data analysis. The purpose of this question is to keep track of who has answered the survey and if you want your results at the end of the study, it will help us to pull the correct information.

_____

End of Block: Default Question Block

Appendix J - Nutrition knowledge questionnaire

Q1 This is a pre-survey. We will use the information you provide us to evaluate the program. We are not judging you in any way, please respond as truthfully as you can.

Q2 Which of the following are macronutrients? Select all that apply.

- [ ] Salt
- [ ] Vitamin C
- [ ] Protein
- [ ] Fat
- [ ] Carbohydrates

Q3 What are functions of protein? Choose one best answer.

- ○ Be the main fuel for the body and introduce omega 3 in the diet
- ○ Be the building blocks of our body and be part of cells
- ○ Be transformed in photo-nutrients and reduce inflammation

---

Q4 What are functions of fat? Choose one best answer

- Be the building blocks of our body and be part of cells
- Be part of the brain and hormones
- Be the main fuel for the body and introduce omega 3 in the diet

---

Q5 What are functions of carbohydrates? Choose one best answer

- Be the building blocks of our body and be part of cells
- Be part of the brain and hormones
- Be the main fuel for the body and introduce fiber in the diet

---

Q6 Which of the following are sources of protein? Select all that apply

- [ ] Beef
- [ ] Almonds
- [ ] Legumes
- [ ] Beans
- [ ] Vegetables
- [ ] Milk
- [ ] Butter
- [ ] Lard
- [ ] Olive oil
- [ ] Sugar
- [ ] Fruit
- [ ] Fish
- [ ] Grains

Q7 Which of the following are sources of Fat? Select all that apply

- [ ] Cheese
- [ ] Almonds
- [ ] Legumes
- [ ] Beans
- [ ] Vegetables
- [ ] Leafy greens
- [ ] Milk
- [ ] Butter
- [ ] Lard
- [ ] Olive oil
- [ ] Sugar
- [ ] Prok
- [ ] Fruit
- [ ] Fish
- [ ] Grains

Q8 Which of the following are sources of Carbohydrates? Select all that apply

- [ ] Beef
- [ ] Almonds
- [ ] Legumes
- [ ] Beans
- [ ] Vegetables
- [ ] Leafy greens
- [ ] Milk
- [ ] Butter
- [ ] Lard
- [ ] Olive oil
- [ ] Sugar
- [ ] Honey
- [ ] Fruit
- [ ] Fish
- [ ] Grains

Q9 True or False. Animal sources is the only source of protein.

- True
- False

Q31 People with Parkinson's can benefit from timing their protein. For example, taking Levodopa 30-60 minutes before eating a high protein meal.

- True
- False

Q10 Which of the following are examples of micronutrients? Choose one best option

- Protein and vitamins
- Whole grains and vitamin C
- Vitamins and minerals

Q11 Which micronutrients are critical in Parkinson's? Select all that apply

- [ ] Folate found in dark leafy greens and beans
- [ ] Vitamin B12 found in eggs and fish
- [ ] Calcium and vitamin D found in spinach, beans, eggs, dairy, and sardines
- [ ] Vitamin E found in avocado, nuts, and seeds

Q12 The best and healthiest eating plan for you is one that maintains you in good health, is optimal for your needs, is flexible, and has a variety of foods, beverages and combinations.

- ○ True
- ○ False

Q13 Eating healthy means to eat and drink from the five different food groups. These food groups are fruits, vegetables, grains, protein, and dairy/dairy substitute.

- ○ True
- ○ False

Q14 Which foods are associated with a rapid progression of Parkinson's? Select all that apply

- [ ] Canned fruits and vegetables
- [ ] Nuts and seeds
- [ ] Coffee and berries
- [ ] Herbs and spices
- [ ] Diet and non-diet soda
- [ ] Ice cream
- [ ] Fried food

Q15 Which of the following describes a healthy plate?

- ○ Half of the plate of fruits and vegetables, one fourth of whole grains, one fourth of healthy protein
- ○ Half of the plate protein, one fourth of whole grains, one fourth of fruits and vegetables
- ○ Half of the plate of whole grains, one fourth of fruits and vegetables, one fourth of healthy protein

---

Q16 The ingredients in a food label are in descending order from the one that weighs the most to the one that weighs the less.

- ○ False
- ○ True

Q17 If the gut is not healthy and has high permeability it could be a risk factor for alpha synuclein deposits in the gut and brain.

- ○ True
- ○ False

Q18 When the layer of mucosa in the gut is very thin, pathogenic microbes (the microbes that make us sick like E.coli) can get into our blood and cause sickness and increase inflammation in the body.

- ○ True
- ○ False

Q19 What are functions of good microbiota? Select all that apply

- ☐ Reduces periods of diarrhea
- ☐ Makes the gut mucosa thinner
- ☐ Increases inflammation in the gut
- ☐ Prevents inflammation
- ☐ Helps the immune system be healthier

Q20 What is dysbiosis? Choose one answer

- ○ When there are more bad bacteria than good bacteria in the gut
- ○ All the bacteria in our bodies and in our gut
- ○ When there are more good bacteria than bad bacteria in the gut

---

Q21 Which of the following are sources of PRObiotics? Select all that apply

- ☐ Yogurt
- ☐ Kefir
- ☐ Vegetables
- ☐ Whole grains
- ☐ Kimchi
- ☐ Beans
- ☐ Pickled vegetables

Q22 Which of the following are sources of PREbiotics? Select all that apply

- [ ] Yogurt
- [ ] Kefir
- [ ] Vegetables
- [ ] Whole grains
- [ ] Kimchi
- [ ] Beans
- [ ] Pickled vegetables

Q23 Which of the following are consequences of bad gut microbiota? Select all that apply

- [ ] Weak mucosa protection of the gut
- [ ] Microbes can enter the blood stream
- [ ] Increases inflammation
- [ ] Strengthens the blood brain barrier
- [ ] More neuron cell death
- [ ] Anxiety and depression

Q24 Which of the following foods can help decrease inflammation in the body? Select all that apply

- [ ] Yogurt with live probiotics
- [ ] Salmon source of omega 3
- [ ] Coffee and tea that contain phytochemicals and flavonols
- [ ] Cinnamon
- [ ] Turmeric
- [ ] Berries
- [ ] Beef
- [ ] Fried foods

Q25 Lack of hydration, or dehydration, can worsen the motor and non-motor symptoms of Parkinson's

- ○ True
- ○ False

Q26 Dehydration can make the brain foggy.

- ○ True
- ○ False

Q27 Which type of fiber is good for protecting the heart and protects against diabetes?

- ○ Soluble fiber
- ○ Insoluble fiber

Q28 Which type of fiber is good for healthy bowel movements and aids in constipation by adding bulk to fecal matter ?

- ○ Soluble fiber
- ○ Insoluble fiber

Q29 Which of the following are sources of insoluble fiber? Select all that apply

- ☐ Skins of fruits
- ☐ Beans
- ☐ Blueberries
- ☐ Whole wheat bread
- ☐ Brown rice
- ☐ Oats
- ☐ Skin of vegetables

Q30 Is there an interaction between the protein you eat and Levodopa medication? Choose one answer

- ○ Yes, protein and Levodopa compete to enter the cell
- ○ No, protein and Levodopa don't interact with each other

Q33 Please write your name and last name. This information will not be shared or included in data analysis. The purpose of this question is to keep track of who has answered the survey and if you want your results at the end of the study, it will help us to pull out the correct information.

_____

End of Block: Default Question Block

Appendix K - Program evaluation

Q1 Hi! Thank you for being part of this nutrition research. The following questions are about the online self-paced nutrition education program. Please rate the following sentences according to your opinion.

Q34 Did you completed the online self-paced nutrition education program?

- Yes
- Some of it
- No

Skip To: Q2 If Did you completed the online self-paced nutrition education program? = Yes

Skip To: End of Block If Did you completed the online self-paced nutrition education program? = No

Q2 Overall the program was relevant for me

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

Q3 Overall the program held my interest

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Q4 Overall the program was worthwhile

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Q5 The modules were easy to use

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Q6 The video lessons helped me learn

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Q7 The handouts of the videos helped me learn

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Q8 The module quizzes helped me learn

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Q9 The length of the modules were just right

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

Q10 The overall design of the modules was appealing

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

Q11 The modules had the right amount of information

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Q12 The program covered the topics I wanted to learn about

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Q14 Do you feel that your participation in the nutrition program will have a positive impact on your journey with Parkinson's?

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Q18 The information in the program was easy to understand

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Q29 This nutrition program led me to feel more motivated to improve my nutrition

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

Q19 The information in the program provided new ideas to me

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

Q20 I've put into practice some of the information I learned in the program

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Q21 I've shared some of the information I learned in the program with someone else

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Q22 The recipes in the program were useful to me

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Q24 Has this nutrition program led you to have more awareness in (select all that apply)

- ☐ Healthy eating for PD
- ☐ Gut health for PD
- ☐ Protein and Levodopa interaction
- ☐ Constipation and hydration in PD
- ☐ Other, please describe in the next question

Q25 If you answered 'other' in the previous question, please describe what other topics did this nutrition program led you to have more awareness of

_____

_____

_____

_____

_____

Q26 Has this nutrition program led you to make changes in the following areas (select all that apply)

- ☐ Eating healthy for PD
- ☐ Include more foods to help your gut health
- ☐ Timing protein and Levodopa medication
- ☐ Include more fiber to aid constipation
- ☐ Change your hydration strategy to help with constipation and normal hydration
- ☐ Other, please describe in the next question

Q27 If you answered 'other' in the previous question, please describe what other topics did this nutrition program led you to make changes in

_____

_____

_____

_____

_____

Q23 I've tried to make some of the recipes from the program

- ○ No
- ○ Yes

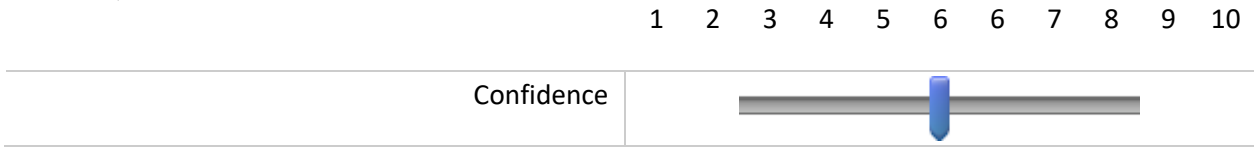
Q15 Do you feel that you will meet some or all of the goals that you set for yourself in this program?

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Q16 Would you participate in an advanced nutrition program on a specialty topic or another nutrition program in the future as a refresher?

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Q13 After participating in the nutrition program, how confident are you that you can take control of your nutrition to help with your Parkinson's symptoms (Scale 1-10, 1- Not at all confident and 10- Extremely confident)



Q17 Would you recommend this program to other people with PD or care-partners?

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Q35
The objectives for module 1 were achieved

Objectives of module

- Understand the different functions of the macronutrients and micronutrients; • Identify foods

that contain protein, healthy and unhealthy fats, and whole grains; and • Identify one goal or action to introduce healthy fats or whole grains.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

Q37
The objectives for module 2 were achieved

Objectives of module

• Understand the different functions of the macronutrients; • Identify foods that contain protein, healthy and unhealthy fats, and whole grains; and • Identify one goal or action to introduce healthy fats or whole grains. • Understand how to read a food label • Understand the ingredients list

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

Q38
The objectives for module 3 were achieved

Objectives of module

• Understand how the gut influences the nervous system • Understand the hypothesis about how PD originated in the gut • Understand what gut microbiota is • Understand foods and behaviors that will help gut health.

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Q39
The objectives for module 4 were achieved

Objectives of module

• Understand how gut permeability affect PWPD • Understand what causes systemic

inflammation • Understand what foods can help decrease inflammation

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

Q40
The objectives for module 5 were achieved

Objectives of module

• Understand how nutrition can help constipation • Understand the difference between soluble and insoluble fiber • Understand why hydration is important • Identify foods that can aid in constipation

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

Q41
The objectives for module 6 were achieved

Objectives of module

• Review protein functions • Remember the sources of protein • Understand the interaction between protein and medication • Understand how to time protein and medication

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Strongly disagree

Q28 Have this nutrition program led you to do anything different in your nutrition? Please describe

_____

_____

_____

_____

_____

Q30 Do you have any recommendations for this program in the future

_____

_____

_____

_____

_____

Q31 What other topics do you think should be included in this program?

_____

_____

_____

_____

_____

Q75 Did you had any barriers while you were doing the program? Please describe.

_____

_____

_____

_____

_____

Q33 Please write your name and last name. This information will not be shared or included in data analysis. The purpose of this question is to keep track of who has answered the survey and if you want your results at the end of the study, it will help us to pull the correct information.

_____

Skip To: End of Survey If Condition: Please write your name and ... Is Not Empty. Skip To: End of Survey.

End of Block: Default Question Block

Start of Block: Default Question Block

Q41 This survey is intended to know what are some of the barriers that may prevent you from participating in the Nutrition Education Program. We appreciate your honest answers, they will help us improve our approach.

Q42 Did you fill out the consent form?

- Yes
- No

Q43 What was the main reason that you wanted to participate in This online self-paced nutrition program for people with PD in the first place?

_____

Q44
This online self-paced nutrition education program for people with PD is in a convenient format for me (online format)

- No
- Maybe
- Yes

Q45 What other format would you like to participate in a nutrition program for people with PD?

- ○ Face to face class
- ○ I like the online format
- ○ Newsletters mailed to me every other month
- ○ Email newsletter with videos on nutrition
- ○ Zoom meeting or Webinar format
- ○ A book with all the information in it
- ○ A YouTube channel where I can see the videos

Q46 This online self-paced nutrition education program for people with PD is of appropriate length (2 videos of 15 minutes and 1 video recipe of 5 minutes)

- ○ Disagree
- ○ Somewhat disagree
- ○ Neutral
- ○ Somewhat agree
- ○ Agree

Q47 This online self-paced nutrition education program for people with PD is convenient for me

- Disagree
- Somewhat disagree
- Neutral
- Somewhat agree
- Agree

Q48 I have enough time to participate in this online self-paced nutrition education program for people with PD

- Disagree
- Somewhat disagree
- Neutral
- Somewhat agree
- Agree

Q49 This online self-paced nutrition education program for people with PD seems appropriate for my and my family

- Disagree
- Somewhat disagree
- Neutral
- Somewhat agree
- Agree

Q50 I feel this online self-paced nutrition education program for people with PD could work for me

- Disagree
- Somewhat disagree
- Neutral
- Somewhat agree
- Agree

Q51 I feel this online self-paced nutrition education program for people with PD would benefit me

- Disagree
- Somewhat disagree
- Neutral
- Somewhat agree
- Agree

Q52 I have other things more important for me and my family right now, so this online self-paced nutrition education program for people with PD did not accommodate to my needs

- Disagree
- Somewhat disagree
- Neutral
- Somewhat agree
- Agree

Q53 Previous experiences with other programs made me not wanting to be part of this online self-paced nutrition education program for people with PD

- Disagree
- Somewhat disagree
- Neutral
- Somewhat agree
- Agree

Q54 I feel this online self-paced nutrition education program for people with PD is culturally appropriate

- Disagree
- Somewhat disagree
- Neutral
- Somewhat agree
- Agree

Q55 How important is nutrition education in Parkinson's disease?

- Not important
- Somewhat important
- Neutral importance
- Important
- Very important

Q56 Are you concerned about nutrition education in Parkinson's disease?

- Not concerned
- Somewhat concerned
- Neutral concerned
- Concerned
- Very concerned

Q57 How would you rate your nutrition knowledge in Parkinson's disease?

- ○ No knowledge
- ○ Some knowledge
- ○ Average knowledge
- ○ High knowledge
- ○ Proficient knowledge

Q58 Would you be interested in acquiring more nutrition knowledge in Parkinson's disease in the future?

- ○ Not interested
- ○ Some interested
- ○ Somewhat interested
- ○ Interested
- ○ Very interested

Q59 Do you think this self-paced nutrition education program could positively impact the health of people with Parkinson's?

- ○ No impact
- ○ Little impact
- ○ Some impact
- ○ Impact only short term
- ○ Impact short and long term

Q60 It is difficult for me to motivate myself to participate in the online self-pace nutrition education program for people with PD

- ○ Not true at all
- ○ Somewhat not true
- ○ Neutral
- ○ Somewhat true
- ○ Very true

Q61 It is difficult for me to motivate myself to use the computer to participate in the online self-pace nutrition education program for people with PD

- Not true at all
- Somewhat not true
- Neutral
- Somewhat true
- Very true

Q62 The amount of time to participate in the online self-pace nutrition education program for people with PD doesn't seem worthwhile

- Not true at all
- Somewhat not true
- Neutral
- Somewhat true
- Very true

Q63 Participating in the online self-pace nutrition education program for people with PD will be rewarding but I have trouble getting myself started

- Not true at all
- Somewhat not true
- Neutral
- Somewhat true
- Very true

Q64 I can't find anything at all appealing or positive about this online self-pace nutrition education program for people with PD

- Not true at all
- Somewhat not true
- Neutral
- Somewhat true
- Very true

Q65 My friends/family do not support my efforts to participate in this online self-pace nutrition education program for people with PD

- Not true at all
- Somewhat not true
- Neutral
- Somewhat true
- Very true

Q66 It is difficult for me to find a good time to participate in this online self-pace nutrition education program for people with PD

- Not true at all
- Somewhat not true
- Neutral
- Somewhat true
- Very true

Q67 My life is so busy that I have trouble finding time to participate in this online self-pace nutrition education program for people with PD

- ○ Not true at all
- ○ Somewhat not true
- ○ Neutral
- ○ Somewhat true
- ○ Very true

Q68 I have difficulty accessing this online self-pace nutrition education program for people with PD

- ○ Not true at all
- ○ Somewhat not true
- ○ Neutral
- ○ Somewhat true
- ○ Very true

Q69 What was your main reason to not keep participating in this nutrition education program for people with PD?

_____

_____

_____

_____

_____

Q70 Do you have any comments on how to promote this program in the future?

_____

_____

_____

_____

_____

Q71 What is your biological gender?

- ○ Male
- ○ Female

Q72 What is your age?

_____

Q73 You are a

- ○ Person with Parkinson's
- ○ Carepartner
- ○ Health professional auditing this course

Q74 Please write your name and last name. This information will not be shared or included in data analysis. The purpose of this question is to keep track of who has answered the survey and if you want your results at the end of the study, it will help us to pull the correct information.

_____

Skip To: End of Survey If Condition: Please write your name and ... Is Not Empty. Skip To: End of Survey.

End of Block: Default Question Block

IMI – Program evaluation

Start of Block: Default Question Block

Q1 Please answer the following questions as truthful as you can.

For each of the following statements, please indicate how true it is for you.

Q2 I enjoyed doing this program very much

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q3 This program was fun to do.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q4 I thought this was a boring program

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q5 This program did not hold my attention at all.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q6 I would describe this program as very interesting.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q7 I thought this program was quite enjoyable.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q8 While I was doing this program, I was thinking about how much I enjoyed it.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q9 I think I am pretty good at this program.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q10 After working at this program for awhile, I felt pretty competent.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q11 I am satisfied with my performance at this program.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q12 I was pretty skilled at this program.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q13 This was a program that I couldn't do very well.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q14 I put a lot of effort into this program.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q15 I didn't try very hard to do well at this program.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q16 I tried very hard on this program.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q17 It was important to me to do well at this program.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q18 I didn't put much energy into this program.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q19 I did not feel nervous at all while doing this program.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q20 I felt very tense while doing this program.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q21 I was very relaxed in doing this program.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q22 I was anxious while working on this program.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q23 I felt pressured while doing this program.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q24 I believe I had some choice about doing this program.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q25 I felt like it was not my own choice to do this program.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q26 I didn't really have a choice about doing this program.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q27 I felt like I had to do this program.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q28 I did this program because I had no choice.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q29 I did this program because I wanted to.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q30 I did this program because I had to.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q31 I believe this program was of some value to me.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q32 I would be willing to do this program again because it had some value to me.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q33 I believe doing this program was beneficial to me.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q34 I think this program was an important activity.

- 1 = Not at all
- 2
- 3
- 4 = Somewhat true
- 5
- 6
- 7 = Very true

Q35
Please complete the sentence in the box below.

I think that doing this program was useful for _____

_____

Q36
Please complete the sentence in the box below.

I think this program is important to do because it can _____

_____

Q37
Please complete the sentence in the box below.

I think doing this program helped me to _____

_____

Q39 Please write your name and last name. This information will not be shared or included in data analysis. The purpose of this question is to keep track of who has answered the survey and if you want your results at the end of the study, it will help us to pull the correct information.

_____

End of Block: Default Question Block